S. HRG. 106–332

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2000

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED SIXTH CONGRESS

FIRST SESSION

ON

H.R. 3037/S. 1650

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 2000, AND FOR OTHER PURPOSES

Department of Education
Department of Health and Human Services
Department of Labor
Nondepartmental witnesses

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2000

TUESDAY, FEBRUARY 23, 1999

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:30 a.m., in room SD–124, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Stevens, Cochran, Gregg, Kyl, Inouye, Hollings, Harkin, Kohl, and Feinstein.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF THE SECRETARY

STATEMENT OF HON. DONNA SHALALA, SECRETARY

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The hour of 9:30 a.m. having arrived, we will commence the hearing of the Subcommittee on Labor, Health and Human Services, and Education.

Today we have a very important hearing on the budget of the Department of Health and Human Services, and we are pleased to be joined by the distinguished Secretary of Health and Human Services, the Honorable Donna Shalala. We have in the second facet of our hearing today the National Institutes of Health. This is always a special occasion, to have such an outstanding, extraordinary, great array of scientists come to a hearing. I am always reluctant to have these hearings go very long with the NIH heads here because they have such important work to do. Of course, it is important as we take a look at what the budget will be for this important branch.

The Congress has been very dedicated to very substantial increases in NIH funding, as you all know, because of the extraordinary results which you have had. Last year we increased by $2 billion, which was an extraordinary sum of money considering the fact that the NIH funding comes from a common pool for health and human services generally, for the Department of Education, for the Department of Labor, worker safety, and very many very important items.

The Congress has consistently, whether the administrations are of one party or the other, taken a more generous look at NIH funding than has the administration. This year it is going to be tougher than ever to find funding which will keep the kinds of applications rolling. I had a private meeting with Dr. Varmus, interrupted a bit of our hearings 2 weeks ago to get a thumbnail as to what is happening.

But I do know that if the funds are not very substantial, it will cut back on the kind of research projects you have. So we are going to do our utmost. But I would urge all of you and everyone in this room to communicate with the Chairmen of the Budget Committees on both houses, in both houses, and the Appropriations Committee Chairmen to have an allocation. That is what it takes for this subcommittee to make the baseline recommendations.

The work in the field is so extraordinary that something is always topical in the headlines. Today's media reports talk about the combination treatment of cervical cancer to cut mortality by half with a combination of chemotherapy and radiation. I am sure we will want to talk about that to some extent.

There have been some remarkable advances on stem cells breaking late last fall, and we have already had three hearings on that subject and I know it will be a matter of some concern again today, although the subcommittee will have a special hearing. The law has a prohibition as to NIH funding being used for the creation of a human embryo or embryos for research purposes or research in which a human embryo or embryos are destroyed.

We have had opinion of counsel from HHS that where the funding is private and the stem cells are extracted that it is then appropriate for the National Institute of Health to fund the research on the stem cells. That is a matter of some concern in a number of quarters, with members of both the House and the Senate having registered dissents on that issue. It is something we will be taking a very close look at in part today, but really in subsequent hearings, to make a determination as to what the law does allow, although the administration has its legal opinion and they operate in that context, or whether there ought to be some modification as to that provision.

We have quite a number of issues. We have just been joined by one of our ranking members of the Democrats in the absence of Senator Harkin, who I know is on his way. Let me yield, if I may, if it is not too sudden—you just arrived, Senator Inouye—for an opening statement.

Senator INOUYE. It is always good to have you, Secretary Shalala. I just want to join my chairman in welcoming you back.

Senator SPECTER. Senator Kyl, would you care to make an opening statement?

Senator KYL. No, thank you, Mr. Chairman.

Senator SPECTER. Senator Feinstein?

Senator FEINSTEIN. Just to say welcome to the distinguished Secretary. I will have my remarks at the question time.

Senator SPECTER. Thank you very much, Senator Feinstein.

Well, welcome again, Madam Secretary. This is your seventh appearance, I believe. You have a long run, a very successful one. We look forward to your testimony.

SUMMARY STATEMENT OF HON. DONNA SHALALA

Secretary SHALALA. Thank you very much.

Mr. Chairman, distinguished members of the subcommittee: I am pleased to be with you today to present the President's budget for the Department of Health and Human Services. With your permission, Senator Specter, I have submitted a significantly longer copy of my testimony.

Senator SPECTER. That will be made a part of the record in full and, as usual, to the extent you are able to summarize it would leave maximum time for questions and answers.

Secretary SHALALA. Thank you very much, and I will summarize it.

What I really want to discuss with you today is the four challenges that we face in the new millennium and the ways in which the President's budget seeks to address them. The first of these challenges is keeping our promise to older Americans to allow them to retire with dignity. An important part of meeting this challenge is offering assistance to Americans who need long term care. Our budget includes a multifaceted initiative designed to provide support to the 5 million Americans who need long term care and for the millions of working Americans who provide it.

Among other provisions, the President's budget invests $125 million in a new National Family Caregiver Support Program in the Administration on Aging. This will provide assistance to about 250,000 families to care for their relatives with chronic conditions and disabilities.

Another important promise to older Americans is the Medicare program. In the 3½ decades since this program was enacted, we have improved both the length and the quality of life for our parents and our grandparents. As we look ahead to the new century, we owe it to the next generation of seniors, including you and me, to make sure that Medicare remains a rock-solid guarantee of high quality health care.

A re-invented Health Care Financing Administration is an important part of keeping that promise. Under the leadership of Nancy-Ann Min DeParle, the new HCFA has completed one of the most challenging years in its history. It has implemented more than half of the 300 provisions of the Balanced Budget Act of 1997 and has approved 50 State Children's Health Insurance plans. It has worked with the States to help implement the Health Insurance Portability and Accountability Act.

HCFA is meeting the serious challenges of the Year 2000 computer compliance. The agency has reported 100 percent of internal mission-critical systems and 54 of its 82 external mission-critical systems as Y2K compliant. Thanks to the help of Congress in providing supplementary emergency Y2K funding, we were able to accelerate our efforts and are confident that 100 of our internal HHS systems will be compliant by March 31, 1999.

The President's Budget builds on the excellent work of Administrator DeParle and her staff through the continuing steps to modernize both HCFA and the Medicare program. While we further strengthen HCFA's management, we will also continue to fight against waste, fraud, and abuse in the Medicare program. Since

1993 we have increased health care fraud prosecutions by more than 60 percent and increased convictions by 40 percent. I want to take the opportunity to thank you, Mr. Chairman, and Senator Harkin in particular for your unwavering leadership and support of these efforts.

Tomorrow, in fact, my colleagues at the Justice Department will join me as we announce a new AARP-sponsored initiative: "Who Pays? You Pay." This program has its roots in what we affectionately call the Harkin grants to reduce fraud and abuse in the Medicare system.

Earlier this month we reported some dramatic new management success. The Inspector General's annual audit of Medicare has found that the estimated Medicare mispayments have gone down by almost 50 percent in just 2 years. The Medicare payment error rate has dropped from an estimated 14 percent in 1996 to 7.1 percent in 1998. Do not get me wrong. We have very important work ahead and lots of it. But we are moving effectively and we are moving fast.

The President's fiscal year 2000 budget includes $864 million for the Medicare integrity program and the health care fraud and abuse control account. We are also resubmitting to the Congress a package of proposals designed to close loopholes in Medicare payment policies that will save $240 million in the next year and $2.9 billion over the next 5 years.

The second challenge of the new century is the need to help America's working families. Nearly 43 million Americans are living without health insurance; 80 percent of them are working full-time. Forty-three million Americans are without health insurance, and most of them get up every day and go to work. The President's budget again allows uninsured workers between 62 and 65 to buy into Medicare. We also want Americans between 55 and 62 who have lost their jobs and their insurance to have a similar opportunity. We are proposing a tax credit for small businesses that seek to insure their workers through a voluntary health insurance purchasing cooperative.

While we work to expand the number of Americans with insurance, we cannot forget the health of those who are uninsured. Our budget includes a very creative new proposal to help communities integrate the care they already provide to the uninsured. It provides communities with $25 million in the next year and $250 million annually for the next 4 years to streamline and help coordinate care for the uninsured and their families.

We are also asking for $1.5 billion for the Ryan White Care Act, an increase of $100 million. Included in that amount is a $35 million increase in the AIDS Drug Assistance Program to help uninsured people with AIDS purchase needed medicines. Our budget includes $171 million to continue our bipartisan efforts to address the AIDS crisis in minority communities.

While we seek to help working families, we must not forget those disabled Americans who want to work, but are prevented from doing so by the risk of losing their health care coverage. Last year we all came very close to agreeing on landmark bipartisan legislation to allow Americans with disabilities to go back to work and keep their health care coverage. This year the President is deter-

mined that we complete the task and pass a law that allows these women and men to take jobs and keep their Medicare or Medicaid coverage.

Mr. Chairman, three-fourths of those who have the ability to go to work are not in the work force because they have disabilities that make it difficult for them to get health insurance. This would offer them an opportunity to keep their health insurance and get into the work force.

We face a third challenge, too, to mobilize the scientific genius, much of which is represented behind me, Mr. Chairman, to make our Nation a healthier and safer place to live. Our budget continues bipartisan progress we are making towards meeting the President's goal of increasing the budget for the National Institutes of Health by 50 percent over 5 years. We are also proposing a $230 million, four-pronged coordinated initiative to prepare for the medical needs and the health consequences of a bioterrorist event.

While I am talking about our role, though, I would like to mention our role in international health. I would be remiss if I didn't mention the importance of the President's request, not under the jurisdiction of this committee, but for the World Health Organization. I want to make this point: that infectious diseases recognize no borders. It is essential that we work with other nations through WHO to address the global health concerns.

Tuberculosis is an excellent example. Thanks to our aggressive national program, TB in U.S.-born individuals declined by 24 percent between 1992 and 1995. But it has increased almost 11 percent among the foreign-born. The only effective strategy for keeping Americans healthy is to invest in the global control of infectious diseases, and TB is an excellent example of this.

Here at home, this budget also invests in our public health infrastructure, and makes important investments in the Centers for Disease Control and Prevention. We propose $65 million to coordinate surveillance activities in the initiatives for emerging infectious diseases, for bioterrorism, for food safety, and through a national electronic network.

Mr. Chairman, the President's budget seeks to keep our promise to America's children by providing them with a safe and healthy childhood. We are asking for $5.3 billion for the Head Start program, an increase of $607 million. We include $1.1 billion for childhood immunization. One of the great success stories in this country is getting our children immunized. We propose a $50 million program of demonstration grants to the States to improve the treatment of asthma in children. Too many of our hospitals and emergency rooms are filled with children with asthma and we need to make an investment there. The budget invests $40 million to help children's hospitals train the medical personnel they need to care for our most vulnerable children. Our children's hospitals and pediatrician's in particular are left out of our training grants because those grants are done through the Medicare program. There are very few children eligible for the Medicare program. So we suggest a direct investment in the training of the next generation of pediatricians to make sure that we have quality health care for our children. We also propose $1.2 billion over the next 5 years to help the

States reach out to children who are eligible for Medicaid or for the CHIP program, but are not yet enrolled.

Mr. Chairman, I cannot talk about the health of our children without mentioning tobacco. Our budget reaffirms our commitment to combat smoking by children. The President is proposing a 55-cent increase in the Federal excise tax on cigarettes. Research has shown us that the best way to keep kids from smoking is to make cigarettes too expensive for them to afford. The budget includes $101 million for CDC to support State tobacco control programs. It provides $68 million for the FDA's efforts to enforce youth anti-smoking efforts.

Finally, we seek to improve the health and safety of our children by increasing access to safe and affordable child care. This is the counterpart to the children's health initiative for working families. Too many working families are left out of child care help because they do not have a big tax liability, but they are above the cutoff for the programs that help people who are moving from welfare to work. If you go directly to work and you do not make very much money in this country, you are unlikely to be able to get child care. This budget proposes that we give those working families child care help.

PREPARED STATEMENT

Mr. Chairman, I have laid before you a blueprint for preparing our health and social service networks to meet the very real challenges of the new millennium. We look forward to working with you and the members of this subcommittee.

I would be happy to answer any questions.

Senator SPECTER. Thank you very much, Secretary Shalala.

[The statement follows:]

PREPARED STATEMENT OF HON. DONNA SHALALA

Good morning, Chairman Specter, Senator Harkin, and members of the Subcommittee. I am pleased to appear before you today to discuss the President's fiscal year 2000 budget for the Department of Health and Human Services.

STANDING AT THE CROSSROADS OF THE NEW MILLENNIUM

What makes my appearance this year before your subcommittee distinct from all the others is that we are not only submitting a balanced budget for the second straight year, but we are also celebrating a landmark bipartisan achievement—last year's budget surplus, the first on the books in three decades. In the past, we have spoken at great length about the need to balance the budget, and thanks to the hard work and cooperation of the Congress and the Administration, we have been able to achieve that goal.

Mr. Chairman, while we can all take pride in helping to achieve this success, we must now look ahead together to the challenges that still confront us. These challenges are many: helping Americans live not only longer but also healthier lives, extending protections to those without health insurance or who are at-risk, safeguarding our public health, and working to better the lives of our nation's children. As we stand at the crossroads of the new millennium, the combination of our fiscal discipline, the expanding economy, and a new age of scientific breakthroughs provide us with a unique opportunity to meet these challenges.

The budget I present to you today begins to meet these challenges through critical investments in the health and well being of our citizens. It is a budget that keeps faith with the President's vision of a 21st Century America where every family can get ahead and no one is left behind.

Mr. Chairman, the total HHS budget request for fiscal year 2000 is $400.3 billion (Outlays). The amount before this committee totals $230.7 billion (BA), of which $38.527 billion is discretionary. This discretionary component represents an increase

of $1.352 billion over last year. Let me now highlight the main components of our fiscal year 2000 budget request.

THE PROMISE OF A RETIREMENT WITH DIGNITY FOR ALL AMERICANS

Thanks to advances in medical science and health care, Americans are now living longer than ever before. By 2030, the number of Americans over 65 will double, from 34 million to 69 million. This change creates a new set of demands on our health care system, from an increasing need for long-term care services to preparing Medicare to meet the needs of an expanding pool of beneficiaries. Meeting these demands will help older Americans live not just longer lives, but healthier ones.

Long-term care

America's aging population, which continues to increase, needs better long-term care. Our budget addresses this need with a multi-faceted initiative to help the five million Americans who require long-term care and to those who care for them.

Studies show that those who need long-term care prefer to remain in their own homes and communities rather than receive care in nursing homes or other institutional settings. The majority of caregivers are women, and one-third have full time jobs. Sadly, research shows that rates of depression among caregivers are significantly higher than those of non-caregivers of the same age. We must assist these caregivers in their difficult task.

Our budget invests $125 million in fiscal year 2000 for a new National Family Caregiver Support program in the Administration on Aging to assist approximately 250,000 families nationwide who are caring for elderly relatives with chronic diseases and disabilities. This investment will enable states to create comprehensive support systems that provide a range of community-based services to caregivers, including quality respite care, information about local services, counseling, and training for complex care needs.

Our budget also provides seniors, as well as younger Medicare beneficiaries, with critical information to help them better understand their long-term care options. We have requested $10 million for a national Medicare information campaign to provide Medicare beneficiaries of all ages with information on the long-term care coverage available under Medicare and Medicaid, private insurance options, and community-care services. The budget also expands access to home and community-based care services to people of all ages with significant disabilities by allowing states to provide Medicaid coverage to people with incomes up to 300 percent of the federal SSI level who need nursing home care but choose to live in the community. This new Medicaid option will help make eligibility for nursing homes and community based services more comparable and eliminate one of the sources of Medicaid's "institutional bias." This long-tem care initiative also includes policies from other Departments, including a tax credit to compensate for the cost of long-term care services; providing the Federal government with the authority to offer private long-term care insurance to its employees at group rates; and an innovative housing initiative to create and integrate assisted living facilities and Medicaid home and community based care.

Nursing home quality initiative

While we develop the means to support those who receive long term-care in home and community-based settings, we must also continue to ensure that those in nursing homes and institutional settings are getting the quality care they deserve. Last summer, the President announced an initiative to strengthen enforcement and oversight of nursing home quality and to crack down on those who repeatedly violate program standards. While key provisions of this initiative are already being implemented, this year's budget will provide the $60.1 million needed to complete implementation of these provisions. Funds will support increased state surveys of nursing homes, Federal oversight and development of a national criminal abuse registry to screen potential employees, as well as the costs of the additional litigation and appeals that result from stepped-up enforcement efforts.

Reforming HCFA management and combating medicare fraud, waste, and abuse

As steward for some of the most important programs for our elders, the Health Care Financing Administration faces the daunting challenge of reorganizing and modernizing while at the same time meeting pressing statutory deadlines for program changes mandated in the Balanced Budget Act (BBA) and the Health Insurance Portability and Accountability Act (HIPAA). HCFA must be highly sensitive to the needs of its customers as it undertakes these reforms. While HCFA's recent reorganization has made some progress in achieving the necessary changes, more needs to be done. The President's budget outlines a five-part reform plan that will

increase HCFA's administrative flexibility while also enhancing accountability, thereby enabling HCFA to be responsive to its customers and serve as a more prudent purchaser of health care. As HCFA begins to accomplish the basic objectives of these reforms, we will also begin reviewing legislative proposals to increase the stability of HCFA's funding in the future.

While we pursue our efforts to strengthen HCFA management, we also will continue our fight against fraud, waste, and abuse in the Medicare program. Since 1993, the government has increased prosecutions for health care fraud by over 60 percent and increased convictions by 40 percent, and I would like to thank the Subcommittee for supporting these efforts so strongly. This budget continues the fight by providing $864 million for the Medicare Integrity Program and the Health Care Fraud and Abuse Control Account, which support the efforts of both HHS and the Department of Justice in fighting fraud and abuse. It also includes proposals to spend Medicare dollars more wisely by eliminating the overpayment for Epogen and excessive mark-ups for outpatient drugs, requiring private insurance companies to provide secondary payer information, reducing the misuse of partial hospitalization services, and making "Centers of Excellence" a permanent part of the Medicare program. In total, these programs will save an estimated $240 million in fiscal year 2000 and $2.9 billion over the next five years.

QUALITY, AFFORDABLE HEALTH CARE FOR AMERICA'S WORKING FAMILIES

Today, too many people are denied the benefits of health breakthroughs because they lack insurance or access to care. We must take steps to ensure that in the new millennium our health care delivery system keeps pace with advances in medical science and provides high quality and affordable health care to every American family. To do so, our budget expands access to health care and health insurance, particularly for our most vulnerable populations.

Increasing access to health care for uninsured individuals

Nearly 43 million Americans lack health insurance. Many of these individuals receive care only sporadically in hospital emergency rooms. To help these people get the primary care and other services they need, the President is proposing a five year, $1 billion initiative to help communities and health care providers to develop integrated systems that can deliver a more coordinated array of health care services more efficiently to uninsured workers. This program would provide $25 million in grants this year, and $250 million a year from 2001 to 2004, to assist over 100 communities in establishing the infrastructure necessary to develop and participate in coordinated care arrangements and finance additional core health services for uninsured workers within integrated systems of care.

Improving mental health services

Every year approximately 44 million American adults experience some form of mental disorder, including 10 million who suffer serious mental illness. In addition, up to 4 million children ages 9 to 17 experience a serious emotional disturbance. Yet estimates show that less than one quarter of these people are treated for their disorders. Our budget includes $359 million for the Mental Health Block Grant, an increase of $70 million, to provide additional funds for states to create comprehensive, community based systems of care for both adults and children. It also provides $31 million for the Projects for Assistance in Transition from Homelessness (PATH) grant program, an increase of $5 million, which will increase by approximately 13,000 the number of individuals served and increase the number of services provided to those already enrolled.

Ensuring access to AIDS therapies (Ryan White)

We have made significant progress in the fight against HIV and AIDS. Due to the widespread use of combination anti-retro viral therapy, the AIDS death rate in 1997 was its lowest in nearly a decade. But the news is not all good. While the overall AIDS death rate is declining, the disease is exacting an excruciating toll in minority communities. In 1997, 47 percent of those newly diagnosed with HIV were African American and 20 percent were Hispanic. We must continue our efforts to expand access to drug therapies and improve the quality of care, particularly in minority communities. The President's budget continues the fight against HIV and AIDS by providing $1.5 billion for the Ryan White Program, an increase of $100 million. Included in this amount is an increase targeted to communities to provide state of the art clinical care to an additional 10,000 people living with AIDS. In addition, the AIDS Drug Assistance Program (ADAP) will receive a $35 million increase to help individuals gain access to combination drug therapy. The budget also continues to build on the effort initiated by the President and this Committee to address the

AIDS crisis in minority communities. The budget for fiscal year 2000 includes $171 million for special initiatives that will be specifically targeted to HIV/AIDS prevention, treatment, and capacity development needs within the African-American and other racial and ethnic minority communities.

Reducing racial health disparities

Unfortunately, members of minority groups are often less healthy than Americans as a whole. Despite improvements in overall health outcomes, minorities continue to bear a disproportionate burden of the nation's disease and illness. For example, the infant mortality rate for African-Americans is more than twice that of Caucasians, and American Indian and Alaska Natives are about three times as likely to die from diabetes compared to other Americans. The President is committed to ending these racial disparities in health status, and the budget provides $145 million to target many other Department resources in the effort to provide health education, prevention, and treatment services targeted to minority populations.

Medicare, medicaid, and the children's health insurance program

Our budget also includes a variety of legislative proposals to expand access to Medicare and Medicaid for groups that would otherwise be denied health insurance for any number of reasons. It allows Americans ages 62 to 65 to buy into Medicare by paying a premium, provides a buy-in option for displaced workers ages 55 to 62 who have lost employer-provided health coverage, and allows retirees between the ages of 55 and 65 whose companies have reneged on their health benefits to buy into their company's health plan. Another proposal would give states the option of providing Medicaid coverage to legal immigrant children, pregnant women, and certain groups of immigrants with disabilities who have entered the United States after the enactment of the welfare reform legislation in 1996.

The Children's Health Insurance and Medicaid programs represent a valuable means of providing health insurance to poor children who might otherwise go without care. But many families are unaware that their children are eligible to receive care under these programs. Our budget will allow states to increase spending by $1.2 billion over the next five years on benefits and outreach and give them additional flexibility to expand outreach efforts through development of new and innovative approaches.

Making work pay for people with disabilities

Our Budget also promotes opportunities for Americans with disabilities. All too often, disabled Americans are prevented from working by their legitimate fears of losing access to Medicaid and Medicare coverage once they go to work. To enable these Americans to work and earn a living wage, our fiscal year 2000 budget extends Medicare coverage, and at the option of states, Medicaid coverage, to working people with disabilities. This proposal also includes new incentives for states to help them start their programs and to link workers to necessary support services. Since President Clinton and Vice President Gore took office, the American economy has added 17.7 million new jobs. However, the unemployment rate among working age adults with disabilities is still nearly 75 percent. People with disabilities can bring tremendous energy and talent to the American workforce, yet institutional barriers often limit their ability to work. The President's budget proposes a historic new $2 billion initiative that removes significant barriers to work for people with disabilities. It includes the Work Incentives Improvement Act, which invests $1.2 billion in providing options for workers with disabilities to buy into Medicaid and Medicare; a new $700 million investment in a $1,000 tax credit for workers with disabilities; and more than double the government's current investment, an increase of $35 million, in assistive technologies that make it possible for individuals with disabilities to work.

MAKING AMERICA A HEALTHIER—AND A SAFER—PLACE TO LIVE

As we enter the 21st century, new threats to our public health are continually emerging. From the challenge of confronting infectious diseases, to the possibility of a bioterrorist attack and the ongoing problems of foodborne illness, we must constantly be vigilant. The only way to successfully combat the public health problems of tomorrow is by investing today in the necessary medical research and public health and disaster response infrastructure.

The international challenge of infectious diseases

If you will permit me, Mr. Chairman, I would also like to speak briefly to the importance of fulfilling our commitment to support the World Health Organization and

the work it does to improve the health of people throughout the world, including our own citizens.

I recognize that funds for the WHO are appropriated to the Department of State through another subcommittee. But those of us responsible for the health of the American people need to understand that the WHO's ability to fulfill its mission and responsibilities can make a real difference in fulfilling our own public health goals. Key areas include the WHO's work in the surveillance and outbreak control of infectious diseases, headed by a distinguished American (David Heymann), the Tobacco Free Initiative, Roll-back Malaria, the elimination of polio, and the Stop TB initiative.

International trade, commerce, and tourism have truly created a global village. Because infectious diseases do not recognize borders, it is increasingly necessary to protect the health and safety of American citizens by investing in a global public health strategy.

Tuberculosis provides a striking example. In this decade, we have had to aggressively combat a resurgence of TB in the United States. We have made extraordinary progress, with the number of cases declining dramatically.

New York City was among the hardest hit. Now, the only new cases are found among the City's immigrant population—among people who were exposed elsewhere.

Working in partnership with the WHO, and providing the necessary resources, we can develop the global strategy that is critical to protecting our citizens and people around the world.

Responding to the new threat of bioterrorism

Terrorism represents a serious threat to the peace and prosperity of our nation. While terrorist attacks can take numerous forms, the threat posed by bioterrorism is particularly deadly, because it can affect a large population, remain undetected for some time, and cause secondary illness or death if the agent is communicable. As the lead federal agency responsible for preparing for and responding to the medical and public health consequences of a bioterrorist event, we are mounting a comprehensive public health effort to combat this deadly threat.

The President's Budget includes $230 million for the Department to undertake a coordinated, four-pronged initiative to prepare for the medical needs and health consequences resulting from a potential terrorist use of biological weapons. First, our budget invests in the infectious disease surveillance infrastructure needed to detect the occurrence of a bioterrorist attack and to determine its cause, including improvements in case reporting, epidemiological and laboratory capacity, and the development of information technology to allow coordination among Federal, State and local public health officials. Second, it funds the purchase of a stockpile of the vaccines needed to treat the most likely biological agents. Third, the budget invests in developing the medical response capability at the local level to respond to an outbreak by training local health providers and supporting the creation of 25 Metropolitan Medical Response Systems. Finally, it provides funds for research and development activities to develop and expedite review of new vaccines and therapeutics and new rapid screens for diagnosing chemical agents.

Creating superior public health surveillance and food safety

Our nation needs a high quality surveillance system to collect and analyze epidemiologic information if we are to be able to respond effectively to a future outbreak of disease. The President's budget proposes to strengthen our surveillance system by providing a total of $65 million to support the implementation of a National Electronic Disease Surveillance Network Initiative (NEDSNI) at the Centers for Disease Control. This Initiative would integrate electronic communications related to surveillance for the Emerging Infectious Diseases ($15 million), Bioterrorism ($40 million), and Food Safety ($10 million) programs and will establish communication links with the public health and medical communities to enable them to furnish timely information on outbreaks of communicable diseases to State and local public health departments and assure better communications among public health entities.

Surveillance is just one of the keys to fighting outbreaks of foodborne illness. Food-related hazards are responsible for as many as 33 million illnesses and up to 9,000 deaths each year. To combat these outbreaks, the budget seeks $29.5 million for the CDC, a $10 million increase, to expand the PulseNet network of health labs which preform DNA "fingerprinting" of disease causing bacteria. In addition, FDA is seeking $79 million to support its food safety efforts.

Expanding medical and health care quality research

Biomedical research has been the foundation of the unprecedented gains we have made in improving the health of both Americans and the world. Last year, the

President made a commitment to increase the budget for the National Institutes of Health, the world's largest and most distinguished organization for biomedical research, by nearly 50 percent over five years, and this Committee responded by passing an increase of almost $2 billion. This year's budget continues the President's commitment and keeps us on the path set last year with an investment of $15.9 billion, an increase of $320 million. The fiscal year 2000 request, combined with last year's 14.6 percent increase, represents a 17 percent increase over two years. This year's request will enable NIH to fund nearly 30,000 research projects grants, the highest total in history.

Along with his commitment to increase funding for biomedical research, the President last year also made a commitment to ensuring that scientific advances are translated into better health care for the American people. The President's budget honors this commitment as well, providing an increase of $35 million for the Agency for Health Care Policy and Research. These funds will be spent on health care research that will enhance knowledge about how to improve outcomes and quality of medical treatment and how to best translate research results into daily practice to improve health care for all Americans.

THE RIGHT TO A SAFE AND HEALTHY CHILDHOOD

Mr. Chairman, the health investments that I have outlined are critical to meeting the challenges that will confront us in the next century. But we must also invest now in what will undoubtedly be our greatest natural resource in the new century, our children.

Curtailing youth smoking

Last year's settlement of the State tobacco lawsuits affirmed the responsibility of the tobacco industry to pay for health care costs associated with smoking. While this agreement was a step in the right direction, there is more that needs to be done to preserve the public health—and to protect our children from the dangers of smoking. It is horrifying to think that over 400,000 deaths each year are due to cancer, respiratory illness, heart disease and other smoking-related illness. It is even more horrifying that three thousand young people will begin smoking each day, and one thousand of them will die earlier than they should as a result of smoking.

Our budget reaffirms our commitment to combat smoking among the nation's youth. First, the President has proposed raising the price of a pack of cigarettes by 55 cents to reduce teen smoking. The budget also includes $101 million, an increase of $27 million, to expand the Center for Disease Control's support for State tobacco control programs. The budget also provides $68 million for the Food and Drug Administration to support outreach and enforcement activities to curtail youth smoking, an increase of $34 million.

Last year, after extensive negotiations, the states' Attorneys General reached a settlement with the tobacco companies that was based in part on recovering the medical costs of those with tobacco-related diseases. Since U.S. taxpayers paid a substantial portion of the Medicaid costs that were the basis for much of the state settlement with the tobacco companies, federal law requires that the federal government recoup its share. However, the Administration will work with the states and the Congress to enact legislation that, among other things, resolves these Federal claims in exchange for a commitment by the states to use tobacco money to support shared national and state priorities which reduce youth smoking, promote public health and children's programs, and assist affected rural communities.

Promoting childhood immunizations

The most cost-effective way to prevent infectious disease among young people is to immunize every child. As a result of the Administration's Childhood Immunization Initiative, the nation exceeded its childhood vaccination coverage goals, with over 90 percent of America's toddlers receiving each basic childhood vaccine. Thanks to these efforts, the incidence of vaccine-preventable diseases such as diphtheria, tetanus, measles, and polio are at all-time lows.

The President's budget provides a total of $1.1 billion for childhood immunization, including $526 million in discretionary funding, an increase of $77 million over last year. These funds will allow the program to provide all the vaccines recommended by the Advisory Committee on Immunization Practices, including vaccines for rotavirus and catch-up vaccinations for hepatitis B. The budget also includes $99 million for global polio and measles eradication, an increase of $17 million, to support the efforts of the World Health Organization to eliminate polio throughout the world by the year 2000.

Advancing innovative treatments for asthma

Over the past 15 years, the number of Americans afflicted with asthma has doubled to approximately 15 million, with the sharpest increase in rates among children under age 5. Asthma is one of the leading causes of school absenteeism, and often results in limitations in activity and disruption of family routines. To begin to arrest this growing epidemic, our budget proposes $50 million in demonstration grants to states to test innovative asthma disease management techniques, derived in large part from NIH-funded research, for children enrolled in Medicaid and CHIP. Participating States will measure success in reducing asthma related incidents such as emergency room visits and length of hospital stays.

Ensuring continued educational excellence in the nation's children's hospitals

Expertly trained pediatricians are a critical ingredient to keeping children healthy. Children's hospitals play an essential role in the education of the nation's physicians, training 25 percent of all pediatricians and more than half of many pediatric sub-specialties. To support the vital efforts that children's hospitals play in training physicians, our budget includes $40 million to provide financial assistance to support graduate medical education at free standing children's hospitals.

Making child care safe, reliable, and affordable

In millions of American families, both parents must work to support their children. In millions of others, single parents must work doubly hard to maintain family income. This Administration, working together with the Congress, has taken numerous steps to support families of all types, ranging from the Earned Income and Child Tax Credits to the Family and Medical Leave Act and the Children's Health Insurance Program. The next step we must take is to help all parents find child care that is safe, reliable, and affordable. This is not only important as a way to support the needs of working families. Safe, quality child care is essential to the healthy development of our children. Study after study provides evidence that investments in quality care can have major benefits for children, their families, and our society.

Let me thank you for having made a down-payment towards the President's child care initiative with $173 million in quality funds and $10 million for child care related research. The President's fiscal year 2000 budget again includes a requested increase of $10.5 billion in mandatory funding over five years for child care programs in HHS, as well as critical increases in the Departments of Treasury and Education. These additional funds will dramatically expand the availability of safe and affordable child care for working families, as well as improve early learning and the quality and safety of child care. The Child Care and Development Block Grant was used to serve 1.25 million children in 1997. With these additional funds, we are committed to increasing the number of children served by more than one million by 2004.

Enhancing head start

Head Start has been and will continue to be one of the Administration's top priorities. This program has been successful in ensuring that low-income children start school ready to learn. Since 1993, enrollment in Head Start has grown by 17 percent. The President's budget invests $5.3 billion, an increase of $607 million, to allow Head Start to serve an additional 42,000 children, bringing the total number of children served to 877,000 and moving forward on our commitment to enroll one million children by 2002. Consistent with last year's Head Start reauthorization, our budget provides funds to improve program quality, enhance staff development, and reduce staff turnover. This request includes over $420 million for the Early Head Start program, which will provide almost 45,000 infants and toddlers and their families with early, continuous, intensive, and comprehensive child development and family support services.

Curtailing violence against women

Each year an estimated 2.1 million women are raped or physically assaulted in this country. The President's budget provides $218 million, an increase of $28 million, to combat this serious problem that affects families across our nation. This includes $102 million for the Grants for Battered Women Shelters program, which will provide approximately 40,000 survivors of domestic violence and sexual assault with counseling, shelter, and other services. Funds will also be targeted to activities designed to change the social norms that condone violence against women.

MANAGEMENT IMPROVEMENTS AND INNOVATIONS

Managing the complex problems that will confront us in the 21st century requires the development of innovative management strategies that enhance productivity while promoting accountability. We have and will continue to work closely with the Congress and this Subcommittee to develop management reforms that allow us to put every dollar to efficient and effective use.

Y2K

As this Committee is well aware, I have taken the Year 2000 millennium problem (Y2K) very seriously. In fact, in September 1998, I informed all of the HHS Operating Division heads that Y2K was this Department's "Job No. 1". With your agreement, I redirected $42 million from other HHS activities to ensure that HCFA had the funds it needed for Medicare contractor renovations. As a Department we have engaged in a series of strong administrative actions, undertaken a comprehensive review of our funding needs to ensure millennium compliance, and encouraged staff throughout the Department to work diligently to see that our equipment, facilities and systems are all Y2K OK. Although I cannot declare total victory today, I can assure you that 85 percent of our mission critical systems are now Year 2000 compliant and I expect the remainder to be fully compliant within the next couple of months. While this part of the work will be completed prior to fiscal year 2000, we must not relax our efforts, and we must continue our work on other Y2K activities including outreach to communities, infrastructure and biomedical equipment remediation, and business continuity and contingency planning. It will take continued, intense efforts, working together with our colleagues in State and local governments and our public and private partners, to overcome this daunting challenge. We cannot allow the millennium bug to impair our mission or disrupt our services to the American people. Therefore, as part of the fiscal year 2000 budget, I am requesting $165 million to ensure that all of our systems are Y2K ready.

GPRA

Our budget submission also includes HHS' fiscal year 2000 GPRA performance plans. We have been working hard to improve our performance plans and our GPRA process within the Department. Our plans are much better than the first set of GPRA plans we submitted last year. They reflect increased involvement of senior staff, increased consultation with our partners, clearer linkages with the Strategic Plan, and the refinement of measures, baselines and targets. Still, there are several significant challenges facing HHS in GPRA performance measurement. We continue to work toward the increased use of outcome measures, to confront complex data issues, and to work closely with our partners and stakeholders in the development of performance goals and measures. We are confident that our GPRA performance plans for fiscal year 2000 are sound ones and we look forward to continued discussions with the Congress on our plans.

THE MOMENT IS NOW

Mr. Chairman, I have put before you today a blueprint for preparing our health and social service systems to meet the challenges of the new millennium. The goals of making health and happiness the defining characteristic of our seniors' retirement, of providing a better future for our children, and of enabling all Americans to live longer and healthier lives are ones that we all share. And like you, I am committed to achieving these goals while maintaining the balanced budget discipline we have all worked so hard to create.

Chairman Specter, Senator Harkin, and members of the subcommittee: I appreciate the support you have provided us in the past and I look forward to working with all of you to meet the challenges before us in this budget. We have much to accomplish, and no time to waste.

BUDGET REQUEST

Senator SPECTER. We will proceed now, in accordance with the practice of the subcommittee, on 5-minute rounds.

Secretary Shalala, our very able staff has prepared two charts which show $18 billion in offsets which are highly speculative, to put it very, very mildly. Last year when you testified there were similar offsets and, not unexpectedly, they did not materialize. When we finally came to terms with the funding for your subcommittee, for your Department and the other Departments under

the jurisdiction of this subcommittee, very substantial funds were added in October in a very, very unsatisfactory way.

I have already been discussing with the Majority Leader the possibility of starting——

[The lights go out.]

I just mentioned the Majority Leader's name. [Laughter.] [Lights return.]

Secretary SHALALA. I think you were making the point that we do not want to do the budget again in the dark, the way we did last year.

Senator SPECTER. Well, that is a good comment.

The effort will be made by this subcommittee to have this bill taken up early on, perhaps even first, reversing the procedures in the past where we leave the toughest for last, and perhaps start with the toughest first. The total discretionary funding this year is $581 billion. The requested level by the administration goes up to $592 billion, which accommodates inflation, but really not much more. The spending caps are at $574 billion. So what we have in effect is $18 billion in offsets which are really totally unrealistic.

I understand that the budget is prepared by OMB and the White House in a very complex way, so I'm not going to spend any time with the limited 5 minutes I have on this round in debating that with you. But what I would like you to do is to tell me, if these $18 billion are not materialized and the share of your Department is $2.7 billion, what will you cut? It sounds good to talk about more Head Start money, which this subcommittee has recommended, and immunization and treatment of asthma, but I would like your expertise on what you cut if we are looking at a budget with $2.7 billion less.

I would ask yet that the administration consider a leadership role in urging that the budget cap be lifted. You come up with $592 billion in discretionary funds, not very high. But that is really what we are going to be looking at. So without taking the time now, I would like you to tell me in writing which $2.7 billion you would cut.

[The information follows:]

Let me emphasize that all of these increases are paid for. In preparing our fiscal year 2000 budget, we worked hard to find ways to pay for our initiatives without spending the surplus. Thus, all of our discretionary spending increases are offset by revenue increases or other offsets.

Many of the mandatory reductions we have proposed not only save money but are specifically designed to reduce fraud, waste, and abuse, particularly in the Medicare program. Overall, since many of the mandatory reductions in the budget are in HHS programs, in some respects it is only natural that these reductions offset increases in the Department's discretionary spending, though as I have noted there are no direct relationships between these reductions and our discretionary request.

We look forward to working with the members of the subcommittee and the authorizing Committees to see that the offsets we have proposed are enacted, thereby making additional resources available to the subcommittee. These offsets will require enactment of statutory language.

STEM CELL RESEARCH

Senator SPECTER. Let me move to, very briefly, this very contentious issue on stem cell research, where we have the opinion of your general counsel, and the stage having been set where the appropriations bill which came out of this subcommittee, since Janu-

ary 1966 Congress has included the prohibition against the creation of human embryo or embryos for research purposes or research in which a human embryo or embryos are destroyed.

We already have your opinion of counsel that private funds are being used to extract the stem cells from the embryos, so that NIH funding is not being used on the destruction of embryos. We had a major battle a few years back on fetal tissue and there is now no limitation on research on fetal tissue if the abortion was not induced for the purpose of providing the tissue.

My yellow light is on, so my question to you is what would your recommendation be as to a possible revision of the bill to avoid ambiguity or legal interpretations where you have these human embryos which are not being used for conception, but are excess and are being discarded? So by analogy to saying you can use fetal tissue if it is not created and abortion is performed for fetal tissue, similarly that research could be done with NIH funding on embryos, even if embryo destruction, so long as these are excess embryos, not to be considered for human life.

Secretary SHALALA. Senator, I think that what we have said in submitting the General Counsel's opinion is that we do not believe that a change in the law is necessary. Let me say that we believe that the General Counsel's opinion is consistent with current law, that we will continue to rigorously enforce the congressional prohibition on funding for human embryo research. But as the General Counsel has pointed out quite carefully, the law allows the kind of stem cell research that you are talking about and the promise of this research is extraordinary.

Let me also say to you that we are very much aware—and the scientists behind me can speak with far more eloquence—of the difficult ethical and social issues that are involved with this research, and we intend to move forward in a careful and deliberate fashion after broad consultation with the Congress and with the bioethical and research community. But the promise of this research is extraordinary.

We will not move forward with funding until we have rigorous guidelines and until we have an oversight process in place. But the promise of this research for the treatment for diabetes, for Parkinson's, for Burton's, for strokes, and for many other medical conditions is just extraordinary, and we believe that we are acting within the law.

Senator SPECTER. Thank you very much, Madam Secretary.

I yield now to our distinguished ranking member for his opening statement and a round of questions. We will put your green light up, Senator Harkin, when you finish your opening statement.

Secretary SHALALA. The lights may go off.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. I appreciate it. Thank you, Mr. Chairman. I will just ask that my statement be made a part of the record.

Senator SPECTER. It will be in full.

[The statement follows:]

PREPARED STATEMENT OF SENATOR TOM HARKIN

It's a pleasure to welcome Secretary Shalala today to testify about the Administration's fiscal year 2000 budget. I found a number of your new initiatives very interesting—but I was very disappointed in the increase the budget requests for medical research.

Last year, this subcommittee was able to provide a record $2 billion increase for NIH—setting a course to double NIH funding in five years. The President's request of an increase of just 2.1 percent doesn't even keep up with medical inflation, let alone continue us on the path of doubling NIH over 5 years. It is a major retreat in the march for medical breakthroughs.

The opportunities are out there, the potential is great. But we have to commit the resources to get the job done.

I was pleased to see that the Administration has requested a substantial increase for the Head Start program. The evidence is very clear that we need to reach children when they are very young. I see that, under the President's budget, over $420 million will be available for the Early Head Start program, which targets children from birth to three years old. Investing in children when they are young will pay off in the long-run.

I also want to commend Secretary Shalala on the results of the annual Medicare audit which found that losses due to fraud, waste and abuse have been cut in half from 1996 to 1998. The audit found that 7.1 percent of Medicare payments, or $12.6 billion were lost to fraud, waste or abuse. This is encouraging but this is no time for a victory lap. The additional tools that the Congress has finally begun to pay off but there is still too much waste in Medicare.

Secretary Shalala, I understand that you will be speaking to senior citizens across the county tomorrow about how to decipher their Medicare statements and ferret out fraud. I am glad to hear that—we have been encouraging you to do just this for a long time. In fact, last year we provided $7 million to your department to create "senior waste patrols" of retired nurses, doctors, billing clerks and others to train fellow retirees in local communities to better detect and report Medicare fraud and abuse. You joined me in Iowa in 1996 to launch this idea. The senior patrols have been up and running for 2 years in 12 states and have been quite successful.

I am also very pleased to see that the budget includes increased funding for food safety, in particular, additional funding for surveillance and upgrades to labs to expand the network of health labs which perform DNA fingerprinting of disease causing bacteria allowing to connect illnesses with specific foods.

And finally, Madame Secretary, I want to thank your working with us on a number of other important initiatives—including fighting the methamphetamine problem in Iowa and elsewhere, and projects to support our Iowa community health centers and rural hospitals.

Thank you, Mr. Chairman—and I look forward to hearing from our witness.

NIH BUDGET

Senator HARKIN. I apologize for being late.

Madam Secretary, again thank you for your leadership. I had a chance to look at your statement and I appreciate your kind remarks on my behalf. A couple of things.

I am sure that we all agree, at least up here, that the NIH budget is woefully inadequate. The 2.1-percent increase has got to be raised and hopefully we are going to find some way to do it. I do not know how, but that needs to be addressed.

Senator SPECTER. Senator Harkin, before you came in I made a suggestion that the administration take the lead in raising the budget cap or making the recommendation. We have $18 billion in offsets which are illusory, and the question I asked the Secretary, if their share would be $2.7 billion, what would they cut? We really ought to face it head-on at the outset with what the budget caps ought to be.

Senator HARKIN. I appreciate that, Mr. Chairman. I would be willing to work with you on that. But I also must tell you that I am a little dismayed that we cannot find the money to meet the research and health needs of our people, but we can find more

money for re-invigorating a Star Wars program that I thought we had tubed a long time ago.

I remember when Senator Hatfield left the Senate a couple of years ago and in his final statement he said: No longer is it the Russians are coming, the Russians are coming. He said: The viruses are coming, the viruses are coming. That has always stuck in my head, and for the life of me I do not understand why this budget is skewed in the opposite direction.

So I think on both ends we could work together on this.

Madam Secretary, I do want to thank you and compliment you for the substantial increase in the Head Start program, especially the Early Head Start program, the birth to 3, $420 million available for that, and I think that is a great investment. I compliment you for doing that.

Again, I want to commend you on the results of the Medicare audit that found that the fraud, waste, and abuse had been cut in half in the last couple of years. That is great progress. Thank you so much for what you are doing in that regard.

The senior waste patrols I guess are out there. We are going to take that nationwide. If you remember, Madam Secretary, you and I, you helped launch this with me a couple of years ago, 2 or 3 years ago, I forget what it was, and it seems to be pretty successful in the 12 States that we have had it, and now we are going nationwide with it.

The budget increases funding for food safety. Again, some of us have legislation pending from the last Congress, reintroducing it again this year, on the food safety program. Of course, your Department will have a great deal to do with that. So I am pleased that your budget increases some funding for surveillance and upgrade of the labs that are necessary to ensure that our food supply is adequate and safe.

Since I was late, I will forego any questions and I will let you go ahead with others.

Senator SPECTER. Thank you very much, Senator Harkin.

We have been joined by our distinguished chairman of the full committee, Senator Stevens.

Senator STEVENS. Thank you very much. I would be happy to wait my time. I know that others were here first.

Senator SPECTER. Well, we always defer to the chairman, Senator Stevens. But it is your call.

Senator STEVENS. I still wait my time.

Senator SPECTER. OK.

We turn now to Senator Feinstein, who was early bird. Senator Feinstein.

OPENING STATEMENT OF SENATOR DIANNE FEINSTEIN

Senator FEINSTEIN. Thank you very much, Mr. Chairman.

I wanted to confine my questions, if I could, Secretary Shalala, to a number of areas. But let me just begin by saying that I agree with Senator Harkin on the cancer research, 2.1 percent, and I really decry the fact that it is as low as it is. I might say, as one who has been active in this area, that it came as some surprise. So I would be hopeful that we would be able to find a way to increase that amount.

If I can, I would like to ask a question on the FEMAT and the census undercount. For the period of 1990 to 1998, in California the Census Bureau has estimated a net out-migration of 13,000, while California's data indicates a net in-migration of more than 755,000, an enormous discrepancy in counting. I would like to ask what HHS might be able to do to provide some flexibility in achieving more accurate data, such as using figures generated by the Department of Finance in determining the FEMAT for California's Medicaid program.

Secretary SHALALA. Senator Feinstein, thank you for that question. I met with your new Governor, Governor Davis, yesterday and had what I thought was a very thoughtful conversation on this issue.

When the program was set up—and this is how we distribute resources and how we reimburse States—it was built on the census, so that every State had their data coming from the same source. What you are pointing out is that, if the census comes every 10 years and there are huge shifts within a State, that State is underfunded often because of that, and some States may be overfunded, depending on what has happened to their population.

The difficulty here is that we need a source of data that is fair to each of the States. We are going back to take a look, does the Secretary have any discretion in this area? We have to look at the statute to see. But if I do have discretion in that area, do I need to go back and offer every other State an opportunity to look at the same new data and make adjustments there?

Third, within the balanced budget, as I pointed out to the very distinguished new Governor of California and his staff yesterday, if we change the formula for one State that means that we need to take money from another State, because within the balanced budget I would have to identify an offset or simply re-jigger the formula for everybody.

I do not have a clear answer. We are going to look at the statute. I understand the problem. But again, it is the issue of whether our laws allow us to be nimble enough to respond to population changes or whether we are locked in because we have certain data sets, so that a State actually has to wait for the new census.

We have throughout the history of this administration increasingly tried to get more flexibility so we could be more responsive when there were changes. But I do not know the answer to the question about whether we can. We certainly are going to look, but we have to look in a way so that it is fair to all the States.

Senator FEINSTEIN. Thank you very much, and I would like to work with you in that regard because I am very concerned.

Secretary SHALALA. We would be happy to work with you.

Senator FEINSTEIN. Another area that I am very concerned, and the reason I voted against the welfare bill was the two-parent work requirement. As you know, California this year faces a penalty of $7 million, but by 2002 that penalty is going to be $770 million. It is huge in its impact on the grant.

Only 24.5 percent of two-parent families in California met the work requirement, as opposed to the 68 percent required by law. My understanding is that 16 other States have not also met that work requirement. So the penalty is going to be enormous.

The question I would like to ask is is there any view of the Department with respect to a penalty waiver from California and other States that fail to meet this. I wrote an op-ed piece which was carried in Sunday's Los Angeles Times, sort of sending a warning to the State of what is faced, because if we face this—the welfare bill is back-loaded and if we face that kind of penalty, the impact on the State is going to be enormous.

Secretary SHALALA. Senator, again, last year the authorizing committees who authorized the welfare bill took a look at the penalties in this area and in fact made them more realistic. What California is facing now, you should have seen the penalties before. They were basically dropping bombs, they were so strong. So the penalties were made more realistic.

We understand California's problem is the size of the two-parent families that are aided. Again, I have indicated that I am prepared to take a look at it. But again, looking at what authority we have and whether we can do as part of the penalty structure some kind of a work-out. The new administration in California is faced with a failure to get on this issue.

Again, for each of these States we believe they ought to be held accountable and there ought to be reasonable penalties. But we also believe that as part of our effort to make sure they keep making progress that we may have to do some work-outs. But we are going to look at it, see what authority we have. But I cannot promise anything. Congress did review it last year and thought they put in place the more realistic penalties. They were very much aware of what the numbers were and what States were in trouble at that time.

PREPARED STATEMENT

Senator FEINSTEIN. Thank you very much.

I see, Mr. Chairman, my time is up. I have a statement that I would like to have inserted into the record at this point.

Senator SPECTER. Thank you, Senator Feinstein, and we welcome you to the subcommittee and back to the Appropriations Committee——

Senator FEINSTEIN. Thank you very much.

Senator SPECTER. Your statement will be inserted into the record at this point.

[The statement follows:]

PREPARED STATEMENT OF SENATOR DIANNE FEINSTEIN

Welcome to the Subcommittee, Secretary Shalala. It is a pleasure to see you here, and I am looking forward to working with you this year to address the many pressing needs that are the responsibility of your department.

Your fiscal year 2000 budget has some bright spots.

First, in proposing to increase the cigarette tax by 55 cents a pack, the Administration has taken a commendable step toward reducing the number of American smokers and alleviating the costs of treating those who presently suffer from smoking-related illness. Everyday 3,000 young people become regular smokers. Every year almost half a million people die from smoking. The CDC estimates that smoking costs $50 billion every year, and part of these costs are covered by the federal government through programs such as Medicare, Medicaid, the Veterans' Administration, and the federal employees' health insurance program. I hope you will help us provide the Food and Drug Administration with clear, comprehensive jurisdiction over tobacco.

Your Medicare cancer clinical trials initiative also is welcomed. Paying the routine health care costs of participating in clinical trials can bring us tremendous advances. Moreover, testimony before the Senate Cancer Coalition by patient advocacy groups and the research community over and over again has indicated that only 2 to 3 percent of eligible cancer patients, for example, are enrolled in clinical trials.

The Administration's budget contains a needed $1.4 billion for a five-year effort to improve enrollment in the Children's Health Insurance Program. Compared with a national rate of 15 percent, California, at 19 percent, has one of the highest uninsured rates in the country among children, and enrollment in CHIP in California has lagged. And as I have written you previously, I remain disappointed in your department's position that children in the 24 states that have established private or "combination" public-private CHIP plans are no longer eligible to receive vaccines under the federal Vaccines for Children Program.

As you well know, the population is aging. With age comes more illness and disability and thus greater need for health care services, and we need to fill in this major gap in our health insurance system and provide long-term care. Your budget presents some needed new initiatives.

Last, the $230 million request for the Department's new 4-pronged effort to prepare for terrorist use of biological weapons is a critical expenditure. In California, for example, there has been rash of threatened releases of biological agents such as anthrax at schools, businesses and courthouses. We need help in understanding and preparing for these threats.

Yet despite these excellent initiatives, there are some disappointments, and I must especially express my disappointment in the Administration's small increase in funding for the National Institutes of Health. On February 2, I wrote the President to point out that the 2.1-percent increase in this budget is far short of the 15 percent needed to double funding over 5 years. Since that time, the National Cancer Advisory Board has said that this budget request will "seriously damage the National Cancer Program" and that the National Cancer Institute would fund 10 percent fewer research project grants under this request. Given that the biomedical inflation rate in 1998 was 3.3 percent, it seems to me that a 2-percent increase will not even keep up with inflation.

Cancer incidence will increase by 29 percent and mortality by 25 percent over the next 10 years due to changing demographics and aging of the population. Leaders of the Cancer March told the Senate Cancer Coalition in September that "cancer has reached epidemic proportions and by 2010 it will reach staggering proportions." They pointed out that the budget of the National Cancer Institute represents 2 percent of the economic burden of cancer which translates to about l cent invested in research for each $10.00 paid in taxes.

As the scientific community makes unprecedented strides in understanding diseases, their causes and treatments, I am profoundly disappointed in the Administration's health research budget, especially for cancer research. What happened to the "War on Cancer"?

Additionally, as you know, our nation is currently in the third year of welfare reform, and the early successes we experienced in moving families off the welfare rolls are giving way to tougher challenges. I saw evidence of this in December when the Department of Health and Human Services announced that California and 16 other states failed to meet the two-parent work requirement under the Temporary Assistance to Needy Families program. In addition, signs are growing that federal child care subsidies for families on TANF will soon fall far short of demand.

As welfare reform implementation continues, we must provide states with sufficient resources to successfully move families from welfare to work. We must also ensure that HHS is implementing the welfare reform law flexibly, with an eye toward helping states succeed rather than penalizing them for failure to attain rigid work requirements. TANF and child care issues will be a major priority for me this year.

Our nation is facing many other problems that need attention.

An estimated 43 million Americans have no insurance, and California's uninsured rate is the 4th highest in the country. How can we address the health needs of America's burgeoning uninsured population?

Medicare faces bankruptcy. How will we get it on a firm financial footing?

While the death rate is declining and we have made great strides in treating AIDS, giving hope to people who formerly had little, AIDS incidence and deaths fall disproportionately on minorities. For example, African Americans, who comprise 12.7 percent of the U.S. population, account for nearly 60 percent of all new AIDS cases. And while the AIDS drug "cocktails" are effective for some people, they are unaffordable for many.

Managed care is ravaging health care. Obstacles are thrown up by insurance companies when patients try to see their doctor. Needed treatments are arbitrarily labeled "cosmetic" or "experimental." Americans have to fight faceless insurance industry accountants to get the health care they have paid for every month. I hope you will join me in working to put care back into health care.

Again, I appreciate your coming here today, and I look forward to addressing these concerns in today's hearing and the coming months.

OPENING STATEMENT OF SENATOR JON KYL

Senator SPECTER We welcome our new member, Senator Kyl, both to Appropriations full and this subcommittee.

Senator KYL. Thank you, Mr. Chairman, and welcome, Madam Secretary. I appreciate the succinct summary of your long statement. It was very helpful. I share the chairman's concern about the offset issue and I am sure we will all look forward to your response to his questions in that regard.

I will also have to leave in about 20 minutes or so and I will submit questions to you and Dr. Varmus relating to the stem cell research issue that might provide some additional guidance for us on that.

Let me confine my questions to a bit of good news from the Department just last week for my State of Arizona and ask you a question about the future of our so-called AHCCCS program. I understand through John Kelly, the Director of the AHCCCS program, which stands for Arizona Health Care Cost Containment System, our Medicaid program, that the Department of Health and Human Services just last week approved a 1-year extension of the State's section 1—it's actually 1115 waiver to operate our Medicaid program.

As you know, this extension enables the State to operate under the existing terms and conditions of the 1115 waiver. Arizona has operated under the waiver authority since the inception of the program back in 1982. During this time, AHCCCS has been a national leader in delivering quality care in an efficient manner. In fact, in a recent study AHCCCS was rated as one of the three most efficient Medicaid programs in the Nation.

While the 1-year extension is very much appreciated, the AHCCCS program is unclear whether all the provisions of the Balanced Budget Act of 1997 will be applied to the State program in 2 to 3 years or whether the waiver authority will exempt AHCCCS from some of these provisions. There are really three related questions which I would like to pose to you.

Arizona is concerned that all of the provisions of the BBA will apply when it seeks a renewal of the waiver in 1 year. Madam Secretary, how does the BBA affect existing 1115 waivers and the renewal process? Is it your intention that in 3 years all section 1115 waiver States must comply with all provisions in the BBA or must renegotiate their 1115 waivers? If States must renegotiate their waivers, will HCFA be willing to waive some provisions of the BBA to allow States to continue operating their existing programs?

If that is all kind of catching you off guard, you are certainly welcome to provide information in writing as you can.

Secretary SHALALA. I will provide it in writing, and we have communicated. As you know, we are working with Arizona on this issue, and we did make an exception last time, in part because of

Arizona's long and successful history in their management of the program.

Senator KYL. I might say, incidentally, initiated by then-Governor Babbitt.

Secretary SHALALA. Thank you. I am sure he will appreciate that. Whatever we do has to be consistent for all States. That is the difficulty of my job. So let me say this to you: We are working with Arizona and we understand their concerns. While I always have to be concerned about precedent, I also think that we have to recognize successful programs when we see them. I will give you a detailed answer to each of those questions, but the context for them ought to be that we really are working with the State. I think it has been successful so far, but we have to continue that work. We have had long internal debates about making certain kinds of exceptions where we do have authority, but sometimes we just do not have the authority.

Again, this restates my fundamental point about building some nimbleness in the program to be more responsive.

Senator KYL. In particular to programs that have been successful, as you pointed out.

Secretary SHALALA. Yes.

Senator KYL. I will look forward to your answers and to working with you in any way that we can to help make this successful program even more successful in the years to come.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Kyl.

Senator Inouye.

OPENING STATEMENT OF SENATOR DANIEL K. INOUYE

Senator INOUYE. Thank you.

Madam Secretary, I wish to join my colleagues in congratulating you on your successful war against Medicare fraud, waste, and abuse. However, during the recent recess, noting that the numbers of physicians who are now refusing to handle Medicare patients have increased, I had small meetings with physicians, and it is not professional poll-taking, but all of them, in response to my inquiries, suggested that it was not the fee schedule, but it was the fact that they had so much paperwork to do and they were afraid that they might be charged for some error.

Do you wish to make any comment?

Secretary SHALALA. In fact I was on the phone last night with the President of the American Medical Association to reassure her. The vast majority, 99 percent, of physicians in this country are very honest and are trying to do the right thing. We think the laws are pretty clear that we have to see a pattern of abuse. The Inspector General, the Attorney General, the U.S. Attorneys are increasingly getting sensitive to the fact that they have to be careful. When you look at what they have actually done, the record is very straightforward and pretty clean that they are looking for patterns.

But sometimes we send out the wrong messages. We lump waste, fraud, and abuse together. We are not careful in our language about people who have made honest mistakes in terms of billing errors. I think what we have to repeat is that we are partners with the health care professionals in this country, that doctors in par-

ticular are doing a wonderful job for our senior citizens, and that we want to be careful both in word and deed with how we handle our programs.

Simultaneously, when I first came up here 7 years ago and I suggested—and Senator Harkin and Senator Specter will remember this—that we were going to wage war on our own overpayments in the system, on the fraud in the system, on the systemic underlying crime in the system, frankly, I got laughed out of the room, because every Secretary apparently comes up and says that. We put in place the most systematic, systemic oversight that this program has ever had. Last year Medicare grew by 1.5 percent. Some of that is attributed to better accounting practices. We said to everyone: This is not an open-ended account. If we catch you committing real fraud, we are going to put you in jail, and we did. If we get overpayments, we are going to put it back in the trust fund.

So, when you put together something that comprehensive, you look like you are overzealous, compared to where you were before. I think that finding the balance between reassuring the very fine professionals that went into medicine and into health for the right reasons and keeping up our rigorous oversight is a delicate act.

Medical professionals have to hear over and over again from the highest officials in this country that we appreciate the work they are doing, that we care about their work. If they think we are acting inappropriately, they ought to tell us specifically. That is too long of a statement, but I think that your question was very important.

Senator INOUYE. I hope that message is being conveyed now.

I have studied your long statement and also listened to your abbreviated statement very carefully. Is there any significance in leaving out violence against women?

Secretary SHALALA. No, not at all, I just assumed that I would get a question on that because so many members of the Committee are interested in that topic. As you probably know, this administration has taken that issue very seriously and this Committee has made substantial investments in battered women's shelters, in funding systems so that health care professionals are working with law enforcement and social service people.

The Attorney General and I chair a major private commission on violence against women, basically on domestic violence. The private sector is very much our partner. The business community is increasingly getting involved in this issue, with television spot ads, and an 800 number that is one of the most successful in American history. If you call, you reach someone who will help you in your own community. So, I think that we have been rigorous and enthusiastic and have expanded the Federal Government's role. I appreciate the question.

Senator INOUYE. Thank you.

Mr. Chairman, may I submit——

Senator SPECTER. Yes, of course, Senator Inouye. We will maintain the record open until the close of business tomorrow for additional questions in writing.

Senator Stevens.

OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. Thank you very much.

Madam Secretary, it is nice to see you here.

Secretary SHALALA. It is nice to see you, sir.

Senator STEVENS. My colleagues, particularly Senator Cochran, know I enjoy seeing you on the courts, and it is nice to be here with you today.

Secretary SHALALA. Tennis courts. [Laughter.]

Senator STEVENS. Tennis courts. I did not say in the courts. I said on.

No other Federal department has the impact on our committee that yours does. Back in 1984, Defense was much higher than your Department, Health and Human Services. If the trend line had continued, Defense would be at well over $500 billion a year. This year it is $268 billion. Your Department is $403 billion.

If there is a dividend from the end of the Cold War, your Department has it. I think that we have to find a way to deal with some of the great problems in your Department, particularly with regard to medical research. Of all the places where I believe that you are being affected by tight budget caps, I think it is in the area of research.

So I hope that we can work together with you in the months ahead to try and find some way to deal with that. I see Dr. Varmus is here. I am going to look forward to talking with him when his turn comes, but I will not address him with questions right now.

I would hope that you would help me on one thing, however, and I will have some questions I will submit if that is all right. But we have run into a problem in Alaska, I am sure it is national, and that is in our small cities, where families are eligible for Federal assistance, the assistance is so segmented, compartmentalized, that there is a maze of Federal and then State programs that are Federally supported, local programs that are Federally supported.

The result is there are a number of offices, even in a small city, where a family must go in order to try to see if they can get the assistance, particularly under WIC, but I think in terms of the whole range of programs, nutritional and health programs that are available for families. It means that they spend so much time going from office to office.

Congress took the initiative and consolidated 80 Federal job training programs into one job center concept. I wanted to ask you if you would be willing to consider developing a pilot program this year to see if we could not find a way to have all of the family assistance programs on a one-stop basis and see how it would work.

We could have a series of things that are available in some of those places that could actually be of great assistance to a family and, with some volunteers, you could also even have some babysitting and other kind of services available while the parents are taking some of the children or one of the children that needs assistance.

But my staff and I—Liz Connell is here—discussed this with our Governor and he would like to recommend that we use Juneau as a pilot area to try and see if we could, using the job center concept, have a family center for programs coming out of your Department

that affect families. Now, it is primarily, of course, of interest to people in the lower income areas and to some of the minority groups in these areas in our State.

I would like to see if you would be willing to work that out and see if we can find a way. I think it would be more cost effective, frankly. But it certainly would be more family-friendly than it is right now. There is sort of stigma in a small town to have to go to place A and then B and then C and then D to get the assistance that some of our people need for their children and for their families.

Secretary SHALALA. Senator, I would be happy to call the Governor and to talk this through with him and then get back to you. In some States they have actually combined their programs. As you have educated all of us, Alaska often has particular situations that make it more difficult to deliver services. I would be happy to call the Governor and take a look at what we could do to develop a model program there. There ought to be no reason why the programs cannot all be delivered in the same location with retrained public servants who know the programs. They can sit with the family and see what the families need for the total family and for what they are eligible.

Senator STEVENS. Well, maybe we are more impatient, Alaskans. We developed the same thing for the Department of the Interior with the Fish and Wildlife Service, the National Park Service, Bureau of Land Management all in one area, so it is one stop to deal with those land management agencies. I should think we ought to be able to do it with the family-related services that you are providing.

Secretary SHALALA. I think so, too, and we would be happy to work with Alaska. I will relate this conversation to the Governor when I call him.

Senator STEVENS. Last, I note that—and I do not want to talk to you at length about it—my good friend Mike Phelps, who was the inventor of the PET scan, is getting the Fermi Award. I would hope that we would find some way, if the Nation has recognized the value of his services in being the co-inventor of that magnificent system, I hope we can find some way to work it out so we can get HCFA to start repaying—paying for the cost of that service for Medicare patients.

But I did send you a letter. I do not want to go into it now. I would like to have a chance to deal with you on that.

Secretary SHALALA. Thank you very much.

Senator STEVENS. Thank you very much.

Senator SPECTER. Thank you very much, Senator Stevens.

Senator Cochran.

OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Thank you, Mr. Chairman.

Madam Secretary, thank you for letting us know the other day that you had approved the Mississippi health insurance program. That is going to be a very vital service, I think, to the children and families in our State.

We also have had an opportunity recently to work with members of your Department in trying to identify ways to save some of the

rural health centers, clinics, hospitals, and small towns who are confronting some very serious problems with proposed rules that are I guess going to be promulgated by the Department under the Balanced Budget Act, which calls for certain cuts to be made in health care spending, mainly in the outpatient service area.

We find that these hospitals are very troubled by the prospect of having to eliminate a lot of their outpatient services and that this may result in the closure of some clinics and the denial of health care services to many of the people who live in the small towns and rural areas. I do not have a magic answer to the thing this morning, but we appreciate the members of your Department meeting with a lot of our providers who came up from the State to talk about this proposed rule just recently.

What is your plan or if there is a suggestion to make to the Congress for either modifications in the law or other action that can be taken to ease the squeeze, the burden that is being placed on the small town hospitals and other providers?

Secretary SHALALA. Senator, we are looking now at what flexibility we have, because Congress gave us some flexibility. We noted in the rule that we were concerned about rural hospitals, and whether they have an accurate coding system, and accounting systems so they code their services correctly and get reimbursed appropriately. We do have some flexibility to protect low-volume rural hospitals in existing law. But before I come back to Congress to suggest that we need other changes, I want to make sure that we have used all the flexibility that we have in current law. Many people in the Department care deeply about rural hospitals and are putting together all the flexibilities we can. That is what we reported to the delegation that came to see us from Mississippi. Let us go through that review first and then we will be happy to communicate with the Committee if we think there are particular issues that involve new legislation. We are going to try to avoid that.

Senator COCHRAN. My only other comment is to congratulate you for your strong support of the Head Start program. In our State of Mississippi that has been a very popular program, and in these same rural towns, small towns and rural areas, it has been especially helpful to students to get an early start in preparation for school. We appreciate the Department's budget request for that amount of money that you have in your budget.

Secretary SHALALA. Thank you, Senator. As you know, many consider Mississippi to be one of the birthplaces of Head Start and we are very proud of the programs and also of the quality improvements that are taking place.

Senator SPECTER. Thank you very much, Senator Cochran.

Senator Harkin wants to reclaim some of his time to ask questions.

Senator HARKIN. I wanted those that came before me to go ahead and ask their questions. I just have three things that I would like to ask, Madam Secretary.

First of all, on the medical research infrastructure in this country, as we will hear from NIH later and as we all know, tremendous breakthroughs are being made every day in medical research. With the new genetic information that we have now and the new

processes, many of the extramural labs that we have across the country are simply inadequate. Many of them are outdated. We need to upgrade those extramural labs.

I have been hearing more and more about this over the last couple or three years and it has reached almost a crescendo in the last several months. The President's budget only requested $30 million for extramural construction. I do not want to mix these up because I am a strong supporter of the facility on the NIH campus. But that has an appropriation of $40 million. So there is more going on the NIH campus right now than for all of the extramural across the country. I do not say that as a way of saying we should take money off the campus.

I am just saying there needs to be more money put out for extramural construction. I will shortly be introducing legislation to authorize greater amounts to go out for extramural construction. I guess my only question to you is your views on that and how you see this playing out, not only during this budget cycle, but perhaps even in preparing for next year and beyond.

Secretary SHALALA. Senator, thank you very much for the question. As you know, the National Science Foundation has regularly documented the huge laboratory needs of the major research universities in particular. I do not know whether to answer you as a former university chancellor or as someone that has to live within budget constraints. Let me answer first within the budget constraints.

Senator HARKIN. I think I would prefer to chancellor. [Laughter.]

Secretary SHALALA. Let me be very candid with you. Within these budget constraints, we obviously barely increase the National Institutes of Health. The President is on his way, though, to meeting his 50 percent goal, in the combination of this year and the huge increase last year. But we, internally and externally, have never been able to make a case successfully to make major investments in the infrastructure, in the building infrastructure, even on a matching basis. We have been more successful with individual States. Governor Tommy Thompson of Wisconsin, for instance, and I developed a matching program in which we raised significant money, $215 million over a 5-year period, and then matched it with private money.

Many public institutions are going to governors and trying to put plans together to invest in their research infrastructure. The competition, quite candidly, internally is always between what the bench scientists need for their research and investments in infrastructure. The scientists will tell you, if they are candid with you, that they would prefer to get the money for their research and let the universities figure out a way in which they can raise the money or find it in other ways to build the infrastructure. It is really bricks and mortar versus the other.

From the point of view of both a chancellor and someone who has to lead these institutions, my view is that we have to find a balance. I cannot recommend to you on behalf of the President. He has made his submission and I must support his budget. But if we are going to expand the National Institutes of Health, we are going to have to simultaneously worry about the infrastructure, the buildings, the laboratories, and the equipment. At the same time, if I

might mention a budget you are not responsible for, the FDA's, we cannot produce all this science and then have the FDA with a small budget and expect them to keep up the approvals. So we have to look at the entire system that we are producing here and invest properly. I would be happy to work with you. I cannot make a recommendation, obviously, on this budget. You can hear the sympathy in my voice, given where I have been at various times, and I never forget where I was before when I do this job. But I am being as candid as I possibly can be.

Senator HARKIN. I understand that. I did not mean to put you on the spot. I just wanted to—again, the idea being that you do recognize that we could work together to try to move ahead in that area, and I appreciate that.

I just have two other things, one building on what Senator Cochran said, a little bit different slice on that. I understand there is a proposed regulation coming out of your Department that would apply new criteria to the designation of the health professional shortage areas. I am beginning to hear a lot about this in Iowa, because once you qualify for that then you get things like community health centers, you get Medicare bonus payments for the providers, rural health program, National Health Service Corps. All these fall in if you qualify.

I am told the proposed regulations dramatically reduce the number of these HPSA's in rural America. The Iowa Department of Health estimated that under the proposed rule we would go from 20 to 6. The National Rural Health Association estimates that nationally 30 percent of these service areas would be lost. Again, for a lot of our people in rural areas, you lose that designation, they lose the bonus payments for the providers, they lose the providers.

I am just wondering why this is happening.

Secretary SHALALA. First of all, as you know from Senator Feinstein's question, populations are shifting and periodically we need to go back and take a look at whether these areas are actually rural now or whether they have actually changed their population. Now, we put a rule out that got a lot of comment. It got so much comment, Senator, that I actually extended the number of comment days by 60 days. I actually extended the——

Senator HARKIN. He is cutting me off. Go ahead, I am sorry.

Secretary SHALALA. We got so much comment——

Senator SPECTER. I was not cutting Senator Harkin off. I was commenting that we have another panel, we have to conclude by 11:30 a.m., and we have been joined by three additional members.

Secretary SHALALA. We got so many comments on this that we extended the comment period another 60 days. We will look at the comments very carefully.

Senator HARKIN. All I can say is, look at them very carefully.

Secretary SHALALA. Yes.

Senator HARKIN. Because the way it is impacting—populations may be shifting, but we have not turned out the lights yet in Iowa.

Secretary SHALALA. No, I understand that. We have a reputation of actually listening to comments. We put out the regs for comment and we often change what we have recommended based on the comments.

Senator HARKIN. One last thing. I wrote you a letter dated January 14th. The one thing I hear about most often in Iowa when it concerns Head Start are the new regulations on transportation for Head Start kids. We now have Head Start agencies in Iowa buying buses to transport Head Start kids when we have rural transit authorities right there that have the buses, that can go out and pick up these kids, take them to Head Start class, and take them home.

So the Head Start agency buys the bus, they use it once a day, that is it, and it sits there. Yet the rural transit has the buses to transport the kids. They have the seatbelts, their safety.

I am told that, you know why they cannot do it, Senator Stevens? Because they do not have an arm that swings out like a bus and says "Stop," and it does not have a flashing light on top. I mean, we have to have some common sense here.

Secretary SHALALA. I agree, Senator. I do not know but I will be happy to check it out.

Senator HARKIN. Help me out. There is a lot of money going out buying these buses.

Secretary SHALALA. Let me find out what is going on there and what the authorities are. I am not sure it is the new regs, but I would be happy to look at that.

Senator HARKIN. Well, we have got to do something, because they are already starting to buy buses when we need the money for the kids.

Secretary SHALALA. Yes; I appreciate it, Senator. Every hearing has a question that was not in my briefing book. [Laughter.]

Senator HARKIN. Look at my letter.

Senator SPECTER. Senator Gregg.

OPENING STATEMENT OF SENATOR JUDD GREGG

Senator GREGG. Thank you.

Madam Secretary, just two questions. One, to what extent have we prepared and are we developing our storage capabilities and preparation capabilities for toxins relative to a terrorist action in the area of chemical or biological, and is it distributed adequately around the country, and is there an adequate toxin capability?

Secretary SHALALA. We are in the process of reviewing that, Senator. We would be happy to keep you up to date on what we are doing. It is part of the national bioterrorism strategy.

Senator GREGG. Well, what are we doing? I guess I am asking, what are we doing?

Secretary SHALALA. We will be doing some stockpiling of appropriate drugs and whatever we need. Whether it is going to be a virtual system, so that we know where they are so that we can move them around the country, or not, I now cannot give you a final answer.

Senator GREGG. Do we have such a stockpile now?

Secretary SHALALA. Some of that is confidential and some of it I can answer, and I will be happy to answer what type of stockpiles we have and if we have them in certain areas.

Senator GREGG. I would like to get an answer. I understand some of it may be confidential, so communicate it to us in whatever way you need to. I would be interested in knowing what our status is on that.

Secondly, what is your position relative to recovering, the Federal Government recovering some percentage of the Medicaid settlements? Maybe you already addressed that.

Secretary SHALALA. I have not. I would be happy to address it. The President spoke to the governors yesterday and here is basically what he told them. The law says that we routinely get recoveries from third parties. Under the Social Security Act amendments of 1968, Congress gave States the authority for suing third parties for reimbursements. They represent the Federal Government in those suits. They collect the money, tell the Health Care Financing Administration what they have collected, and send us the appropriate share under the Medicaid law. States have, over the years since 1968, routinely sent us billions of dollars. The tobacco settlements are covered by that law. What the President pointed out was that he is prepared to work with Congress and with the governors. He does not necessarily want that money back into the Federal Treasury. He wants to make sure, because the issue here is reducing smoking among children, that the money is spent on appropriate health concerns.

Last year as part of the tobacco bill we actually worked out an agreement with the governors on a menu of things that the money would be spent on. But our first position is the legal position we must take under the law. Second, the President has emphasized to the governors that he expects to be able to work something out with the Congress and with them so that they can keep the money, but spend it on health-related needs such as tobacco control and tobacco prevention.

Senator GREGG. So first, what percentage do you expect the Federal Government to recover of the recoveries that the States are having? Secondly, I take it that percentage, you expect the Federal Government to set up a regulatory structure to direct its expenditures for health care activity?

Secretary SHALALA. No, we are not necessarily talking about a regulatory structure. That is the kind of thing that we discussed. If you take the percentage the Federal Government pays of Medicaid, it is 57 percent.

Senator GREGG. So is that the amount you expect to recover?

Secretary SHALALA. That is the amount that we will go to the table to start negotiations. But Congress, the governors, and the administration need to sit down and talk this through. I do not expect to set up a huge bureaucracy as a result of this. We want to make sure that the money is spent to reduce teenage smoking and for other health-related needs. We do expect the governors to administer the money, but there will have to be some guidance and some agreement on how it will be spent.

Senator GREGG. So if I understand what you are saying, it is that, take hypothetically if a State were to recover a billion dollars, you would expect the Federal Government to have control over 57 percent of that, which would be $570 million, and that might be under the control of the State governor, but you would expect the Federal Government to have a say in how that percentage was spent?

Secretary SHALALA. Senator, I cannot respond to a hypothetical. You are trying, fairly, to pin me down on specifics. Since there is

under the law a share that does in fact belong to Federal taxpayers, we ought to work out a piece of legislation that ensures—if the Congress decides that this money ought to be kept in the States—that that money is designated by the States. The governors reassured the President yesterday that they actually intended to do that and they would be happy to sit down and talk this through. So I think we can work it out with Congress. We go in with open minds about percentages and other things. We would like to work it out in legislation.

The President said that having the money stay in the States is fine with him, but he believes that the money ought to be spent on tobacco control, on tobacco-related issues, on health issues. I heard no objection in the discussion about that. On the details, I think that we would leave it to your leadership to sit and talk with us and with the governors to work this out. We would like to work it out.

Senator GREGG. Thank you.

Secretary SHALALA. You are welcome.

Senator SPECTER. Thank you, Senator Gregg.

Senator Kohl.

OPENING STATEMENT OF SENATOR HERB KOHL

Senator KOHL. Thank you, Mr. Chairman. I have a single question for Mrs. Shalala.

As you may recall, at last year's hearing I spoke with you about legislation to require criminal background checks for long-term care workers. Since then I have been pleased to work with you on this, and I am glad to see that the background checks for nursing home workers were included in the budget.

However, I feel strongly that it is equally important to require checks for all long-term care workers. After all, it does little good to stop a criminal from working in a nursing home if they can then go on to work in a home health care agency.

Why did the administration stop short of requiring checks for all long-term care workers, and would you support an expansion of the background check to other long-term care settings?

Secretary SHALALA. We are reviewing the issue. We will get back to you, Senator Kohl. For some reason, it was much more straightforward to go forward with the nursing homes as opposed to all of long-term care. But we are prepared to work with you on this issue. We want to be able to have these databases and to check these records.

PREPARED STATEMENT

Senator KOHL. I thank you.

I thank you, Mr. Chairman. I have a prepared statement to submit for inclusion into the record at this time.

Senator SPECTER. Thank you very much, Senator Kohl, your statement will be included in the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR HERB KOHL

Thank you, Mr. Chairman. And I want to thank you, Secretary Shalala, for once again appearing before this Subcomittee. It's always good to see you, and I look forward to discussing the fiscal year 2000 budget with you in more detail.

As we approach the new millenium, it is appropriate that we take a close look at our values and needs, where we are and where we want to be. The first budget of the 21st Century should reflect these goals—and we should send a strong signal that we will make meeting these goals our top priority.

With our economy continuing its record growth and our budget in balance, we have the unique opportunity to focus on helping our nation's most vulnerable citizens. First, we must set our sights toward creating the best opportunities possible for our children. As more and more parents join the workforce, we must ensure that children have a safe, stimulating place to spend their time, before their school-age years, both before and after school hours, and during the summer months. I am pleased to see that the President's budget again includes increases for the Child Care & Development Block Grant and Head Start. These programs help ensure that children have a safe, educational, and recreational place to go when they are not in school.

I am also pleased to see that the Administration is taking its responsibility of nursing home oversight very seriously in this budget. Our nation's senior citizens have made our country what it is today—they deserve to be treated with respect, care and dignity. The Administration's Nursing Home Quality Initiative, in conjunction with legislation requiring background checks for nursing facility workers, will help ensure that our elderly receive the best quality care possible. I look forward to working with you, Secretary Shalala, to make these proposals a reality.

Again, thank you for appearing before the Subcommittee today. I am eager to hear about the fiscal year 2000 budget in more detail.

OPENING STATEMENT OF SENATOR ERNEST F. HOLLINGS

Senator SPECTER. Senator Hollings.

Senator HOLLINGS. Just one question. Thank you, Mr. Chairman.

Madam Secretary, the community health centers have been doing an outstanding job with respect to the uninsured. However, we find, under the balanced budget agreement of 1997, that they continue to cut Medicaid reimbursement. So, in order to take up the slack, community health centers have been forced to spend money allocated for uninsured patients to take care of Medicaid patients. Again, we had to increase funding by $100 million last year, and this year you are requesting only a $20 million increase, even in light of the substantial Medicaid cuts.

I hope you would look at that, and we might have to support more money going into the health centers, because what we are really doing is we are cutting back on the Medicaid costs, but then the health centers are taking their good money and it is not getting to the uninsured and therefore they are not getting the coverage.

Secretary SHALALA. Senator, there are a number of things going on there, and I agree with you. The issue here for the community health centers is, as the States move their Medicaid recipients into managed care they pull out paying customers from the community health centers. The community health centers are left with a larger population of the uninsured. One of the proposals that we have in this budget would increase the amount of money that goes to community health centers. In addition, we would help them build themselves into networks in the community, so that they can refer people to specialty clinics, to academic health centers, and to public hospitals. The importance of this is we still have too many people that are not going to get their basic care at the community health center, but at an emergency room. Community by community, we need a seamless system to care for the uninsured. Remember, I am

not talking here about health insurance. I am talking about the health care system that is there working better so that people go to community health centers for basic care and then are automatically, if they have a chronic illness or need an operation, linked up to the specialties that they need. So in our investments in community health centers we have to watch our basic care system in this country for the uninsured. As we pull out Medicaid recipients, as is happening in California, for example, Senator Feinstein, the population of the uninsured is larger as a percentage in those clinics and they need different resources. But the uninsured also need a link to specialties and to specialty hospitals. We need this system to work in a smooth way for the uninsured, so that they are not confused about whether they should go to an emergency room. They need to get to the right place at the right time. The health care system has to work even though it is fragmented.

Senator HOLLINGS. Thank you, Mr. Chairman. I will submit my other questions.

Senator SPECTER. Thank you very much, Senator Hollings.

Before we move on to our next panel, Madam Secretary, one parochial matter that I would like your help on. On August 18th, I wrote to HCFA Administrator Ms. DeParle concerning the assessment made against Pennsylvania's disproportionate share hospital program. I would appreciate it if you would expedite a response to that.

One question which I discussed for a moment with Senator Stevens. According to the Congressional Research Service, there is between $3 billion and $3.5 billion in unspent temporary assistance to needy families, welfare, block grant funds, at the end of fiscal year 1998. The question comes to my mind whether those unexpended balances might be rescinded, might be made available for NIH, Head Start.

Senator Stevens did not say no. In fact, he sort of said yes. Senator Stevens?

Senator STEVENS. Well, as a matter of fact, Madam Secretary, those are funds according to our information that the States did not ask for and they would have to match them in some instances if they took them. If they are in that pipeline, we do not want to see someone else put their hands on them. We would like to have them for medical research. I would urge you to take a look at that.

Someone is in the budget process going to seize that. I do not believe they should leave this subcommittee's jurisdiction. I agree with Senator Specter, we should work together to see to it that those budget funds are used to meet the needed areas of research, rather than to have them moved into some other portion of the budget.

Senator SPECTER. That would eliminate the need for the next panel, too, Madam Secretary. [Laughter.]

Secretary SHALALA. Senator, I would not want to block your opportunity to hear from my very distinguished colleagues at NIH. Let me answer quickly that these are the block grant funds that went to the States for the TANF program, the new welfare program.

Senator STEVENS. Right.

Secretary SHALALA. Half the States have drawn down their money. The other half are in the process of doing that, including putting some of the money in rainy day funds.

Senator STEVENS. Well, that is not exactly right. They have to take them and match them and use them. If they are going to take them and match them and put them in the bank, why should we borrow money so they can put it in the bank and earn money?

Secretary SHALALA. Well, Senator, because that was an eligible activity to which Congress agreed. I would be happy to have a lengthier conversation about these funds. I think the next quarter will show that the governors are drawing these down faster. A rainy day fund was a legitimate expenditure for TANF. I want to be very protective because the governors are now faced with a welfare population which needs much more intensive expenditures, such as substance abuse problems, and are harder to get off welfare. Many States were putting these moneys aside for that process. Half the States have already drawn it down. The other half that has not has plans for the money. So we would not want to encourage you to take that away. If I knew of any other pot of money, I would identify it immediately for my colleagues at the NIH. I want to reassure you of that.

Senator STEVENS. Mr. Chairman, if I may be full and open with you, the President asked me to agree to reprogram some funds for the problems related to Hurricane Mitch from defense, and we objected to that. He said, well, where should we get them? I gave him a list of four or five areas and one of them is this.

I think that those funds are annually augmented. Those States that did not take the moneys last year are going to get more money this year. Now, we are not going to have them take that out and put it in the bank. Now, that is all there is to it. We cannot work this system that way, because we still are borrowing money on this budget.

Sorry about that.

Senator SPECTER. Well, thank you very much, Senator Stevens.

The point is that those were unused at the end of fiscal year 1998 and I do think that would be relevant as to the inability of the States to take the money from last year when current funds are available. Well, it is something we want to pursue. It is a very substantial sum of money, and I think we made a little progress.

Secretary SHALALA. Thank you, Senator.

Senator SPECTER. We really appreciate your being here, Madam Secretary.

Secretary SHALALA. Thank you, Mr. Chairman.

Senator SPECTER. Thank you. Thank you very much.

ADDITIONAL COMMITTEE QUESTIONS

There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

USER FEES

HCFA's fiscal year 2000 budget has once again proposed a number of new user fees, totaling $194.5 million, to supplement its program management budget. The enactment of user fees would offset the appropriation by an amount equivalent to the estimated collections.

Question. In light of past resistance from the provider community to the proposed user fees, what alternative revenue sources should we consider?

Answer. The proposed user fees make good programmatic sense and fit within our goal of increasing the efficiency of our payment systems. For example:

Charging enrollment fees to enter fee-for-service Medicare would discourage "bad actor" providers from entering Medicare. Charging facilities a fee for their initial survey would discourage "fly-by-night" facilities from seeking entry into the Medicare program. A few for duplicate claims or paper claims would reduce the costs of processing claims and increase the efficiency of HCFA's payment system. Processors in rural areas with no electronic claims capability will have the opportunity to receive special waivers from the paper claims user fee. In addition, we believe that health care providers receive significant revenues from participation in Medicare, and the proposed user fees are small in comparison.

This year funding alternatives are not needed because, in the absence of enactment of the user fees, the request for Program Management is for the full amount needed to operate the program. HCFA is engaged in a management reform initiative, highlighted in the President's budget, that will help us make the most efficient use of our resources and adapt to the changing health care market.

In recent years, HCFA's Program Management budget has remained relatively flat, while our legislative and operational challenges have continued to increase. Congress began to address this last year when HCFA received more than an 8 percent increase in program level to fund important activities such as BBA and HIPAA implementation and Y2K remediation. HCFA's fiscal year 2000 budget request provides for a 6.0 percent increase over fiscal year 1999, which is necessary to meet HCFA's expanding programmatic responsibilities, as well as priority base activities.

We thank Congress for providing the fiscal year 1999 increase, and we look forward to working with Congress to address any further concerns and to ensure that HCFA receives its full budget request for fiscal year 2000.

Question. Can HCFA officials propose outreach activities or implementation strategies that might be used to asoften their concerns?

Answer. If the user fees are enacted, HCFA may propose outreach activities and implementation strategies. The agency normally undertakes these kinds of efforts to inform its partners and stakeholders of programmatic changes. It is their belief that such educational activities would allay many provider concerns over the proposed user fees.

Program management user fees

HCFA is proposing enrollment and claim processing fees of $92.8 million in fiscal year 2000. It is also proposing to collect $37.7 million in fiscal year 2000 from managed care plans both for filing initial applications and renewing contracts.

Question. What are the additional costs associated with the implementation of the claims processing user fees? Specifically, will implementation tie up contractor resources so that other HCFA initiatives would be delayed?

Answer. There will be some costs to Medicare contractors to make the software changes necessary to set up a fee charging and tracking system. Although these activities are new, they will not be so extensive as to impact the implementation of any other HCFA initiative.

Question. How many providers will be affected by the fee for the submission of paper claims? Apart from rural providers and those with a limited number of Medicare claims, who is most likely to be affected by the fee on paper claims?

Answer. Although HCFA does not have a precise count of the number of providers that submit paper claims, approximately 17 percent of all claims submitted are on paper. The proposed language stipulates that if a provider does not have the necessary technological equipment or, if the provider, regardless of location, submits a very limited number of Medicare claims they be allowed to request a waiver to this fee, thereby ensuring that these providers are not impacted by this fee. The providers that will most likely be affected by this fee are those with a large number of Medicare claims that possess the technological equipment necessary to submit claims electronically but choose not to.

Question. What are a provider's costs when switching from paper to electronic submission?

Answer. The software required to transmit claims electronically is free, as is the technical support to answer provider questions about this software. Additional costs would be incurred for a personal computer, modem and phone line. HCFA believes that all but a very small percentage of providers have this equipment already. The Administration's legislative package includes language allowing providers to request a waiver from this fee if they lack the necessary technological equipment.

Question. Does HCFA expect an increase in the number of paper claims, perhaps duplicate submissions, due to confusion surrounding millennium compliance?

Answer. Yes, the agency does expect an increase in the number of paper and duplicate claims arising from confusion surrounding millennium compliance. HCFA's fiscal year 2000 budget request includes additional funding for the Medicare contractors from the Public Health and Social Services Emergency Fund to cover this contingency. The agency believes the impact of millennium confusion should dissipate early in the year and the fee for processing paper and duplicate claims will not be imposed until the second half of the fiscal year. If this is not the case, HCFA will reevaluate the timing of the implementation of the user fee.

Question. What would be the average application fee for those managed care organizations seeking to participate in Medicare? What were the assumptions that were made in calculating the amount?

Answer. The application fee for managed care organizations would be about $55,000, or the cost of two-thirds of an FTE. Reviewing an organization's application, and its ongoing operations, is a very labor-intensive process. HCFA staff visits the organization to conduct a legal review of the entity and its administration. This includes monitoring for fiscal soundness and all other requirements that the plan must meet to participate in Medicare. Agency staff also conducts an in-depth review of the plan's health services delivery network, marketing materials, benefit packages, and enrollment & disenrollment procedures. Ensuring they meet the requirements to become a Medicare managed care organization is essential in determining that the organizations are in compliance prior to treatment of beneficiaries.

Question. Wouldn't plans perceive this application fee as an additional barrier to participating in the Medicare + Choice program?

Answer. HCFA assumes providers will recognize that this fee is not a barrier to participation, but a normal cost of doing business that is similar to other fees that they incur in their day-to-day operations in the private sector.

Question. Could the review of a plan's application be privatized, i.e., through use of a private sector accreditation organization that would collect fees for its work?

Answer. While this could probably be done, it seems to make as much, if not more, sense to make HCFA responsible for this workload since the agency already performs these activities, and already has a system in place for charging and collecting this type of fee.

State survey and certification user fees

Question. What is the expected cost, by type of provider, for certification and recertification?

Answer. The proposed law user fees would cover 100 percent of HCFA's costs for the initial survey and one-third of HCFA's cost for recertification. These user fees would total $65 million. The table below displays the approximate total expected cost by type of provider.

Provider type	Total number of surveys	Total cost
Skilled Nursing Facilities (SNF)	1,821	$9.0
SNF/NF	15,056	35.3
Home Health Agencies	9,122	12.7
Hospitals	508	.7
Non-accredited Hospitals	165	.4
Others	4,205	6.9
Total	.....	65.0

Note: Numbers are rounded for presentation purposes.

Question. Do these costs vary by state or by region?

Answer. Yes, costs would vary by State. This is due to differences in surveyor salaries and the indirect costs.

Question. Are these survey costs expected to be a burden on small or rural providers? If so, how would this be addressed under the proposal?

Answer. In keeping with the growing government-wide trend of charging user fees, we believe that charging these fees is reasonable and will not impose an undue burden on small or rural providers. The fees will vary by the size of the facility, but will be the same for the same size facility state-wide. These fees will allow us to oversee the Medicare program, including the significant legislative changes, while minimizing the need for discretionary budget authority.

Increase Medicare+choice User Fees

Question. How will HCFA prioritize its efforts to educate Medicare beneficiaries if these activities are level funded in fiscal year 2000?

Answer. HCFA has an eight point National Medicare Education Program to explain Medicare+Choice. This program consists of beneficiary mailings, toll-free telephone lines, Internet activities, national training and support for information givers, national publicity campaign, State and community-based special outreach and education, enhanced beneficiary counseling from State health insurance assistance programs, and targeted and comprehensive assessment of the education model. Funding goes first to cover the beneficiary mailing, telephone service and the Internet. Level funding would mean we would have to limit or even forgo activities in the other areas listed.

Question. Has the user fee been seen as deterring participation in the Medicare+Choice program by managed care provider groups?

Answer. Though managed care organizations are unenthusiastic about the user fee established in the Balanced Budget Act, we have seen nothing to indicate that the Medicare+Choice user fees are deterring new applicants from participating in the program. Furthermore, we have seen nothing to indicate that existing contractors have contemplated leaving the Medicare program as a result of the user fee provision.

Question. HCFA sought expedited review and approval from OMB for a "bounce back form" to solicit reactions from users of its Medicare+Choice website. Was this granted? If so, was useful information gathered and changes made?

Answer. We have sought expedited clearance on two forms for www.medicare.gov. In the fall of 1998, we sought expedited clearance for a bounceback form to obtain feedback on the Medicare & You handbook on the website. As of the end of February, we have received over 9,500 responses to the form. We have received feedback that is being incorporated into revisions of the handbook for next year. We more recently sought expedited clearance for a bounceback form for the overall www.medicare.gov site. The intent of this form is to collect feedback on the overall site. This form will be up on the website within the next few weeks.

Question. HCFA is seeking nominations for a Citizens Advisory Panel to advise the agency on effective educational programs. Please provide more information on the role of this panel, expected benefits and projected costs. How will it differ from information initially gathered through focus groups, interviews, and expert evaluations?

Answer. The Citizens Advisory Panel on Medicare Education will focus its review on the National Medicare Education Program and our other efforts to help Medicare beneficiaries, and those who assist them, find accurate and current information about new Medicare options and benefits under the Medicare+Choice program. The panel will also identify best practices in consumer health education that could enhance our efforts to inform and assist Medicare beneficiaries about their health plan options. An annual report to the HCFA Administrator will summarize the panel's findings and any recommendations the panel may provide.

The panel will consist of 10 appointed members from among authorities in disability and chronic disease interests, minority populations, health consumer interests, seniors' organizations, health communications and policy, research and philanthropic organizations, health insurers and plans, employer groups, and health providers. Additional participation is expected from other federal agencies with an interest in these issues.

The panel will meet quarterly and comply fully with the Federal Advisory Committee Act, including provisions for open public meetings. The current cost estimate is about $45,000 per meeting, including travel costs, small honoraria, and development of background materials.

This panel will complement, rather than replace, HCFA's existing efforts for Medicare beneficiary education. For example, the alliance network of over 100 national health-related organizations currently helps HCFA to disseminate materials and understand current conditions in the community and the marketplace; however, the alliance network does not provide policy guidance or recommendations for future action, nor does it provide HCFA with broad exposure to best practices. HCFA's own evaluation and assessment activities, such as focus groups and expert evaluations,

will continue to provide important information into existing campaigns, but will not provide the kind of broad expert input that can occur only through a formal advisory committee compliant with the Federal Advisory Committee Act.

CHILDREN'S HEALTH INSURANCE (CHIP)

Question. What types of CHIP outreach activities have states undertaken to date?

Answer. States are actively seeking improved methods to simplify their enrollment process and to design innovative strategies to reach out to eligible populations of uninsured children. Listed below are successful and/or promising outreach strategies which States believe are resulting in significant enrollments:

Alabama

Developed many innovative partnerships. One of the more creative is between South Baldwin Regional Medical Center-Gulf Shores and the U.S. Postal Service (USPS). This is the first hospital in the nation to be selected for the USPS partnership program. The program assigns key postal employees to work full time on community projects such as outreach at non-traditional sites during non-traditional hours and providing brochures, posters, and applications to medical and dental offices.

Delivered an extensive physician CHIP training program throughout the State. A variety of health organizations have received training and information on the AL-Kids CHIP program. This has been an effective approach in distributing applications and receiving referrals of eligible participants.

Florida

Convened focus groups to facilitate development of materials for families, including Hispanic families and those with special needs. For example, migrant farm workers assisted in developing an easily-readable, single-page application form and in explaining issues of great concern to immigrant families with eligible children.

Published CHIP materials in both English and Spanish, and maintains a toll-free number with access to workers who speak Creole, Spanish, and other languages to help families fill out the application form or answer any questions. A multi-media campaign was also produced in Spanish and English and aired on both network and cable television channels.

Iowa

Contracted its outreach program to a small marketing firm, implemented statewide training, distributed thousands of brochures to schools, providers, and other agencies.

Received considerable support in enrolling children from the Maternal Child Health (MCH) and Women, Infants, and Children (WIC) programs.

Promoted cultural competence by maintaining a toll-free number that is staffed by Spanish-speaking individuals.

Louisiana

Developed major media contacts to provide opportunities for State CHIP program representatives to appear on local TV and radio programs, including the health segment of the news.

Distributed a tri-fold brochure with an attached enrollment application, which is credited as being the most important aspect of outreach. These brochures are placed in high traffic locations, such as libraries and post offices, and more unconventional locations such as apartment laundry rooms.

Maryland

Shortened the processing time for enrollment determinations by delegating this responsibility to the local health organizations.

Distributed program information to every facility in the State which provides services to children.

Enlisted broad-based partnerships, both private and public, to facilitate program information dissemination and identification of uninsured children.

Massachusetts

Developed regional outreach networks focusing on local grassroots outreach, bringing community organizations together with providers and State agency outreach/enrollment staff. These networks, funded by mini-grants from the State, tailor outreach to the needs and wants of specific communities and regions of the State and meet monthly to exchange program information and best practices in reaching and enrolling the eligible population.

Collaborated with local housing authorities to identify families in need of insurance for children through their annual housing recertification processes and through informational meetings and materials tailored to the languages and cultures served by specific housing sites.

Michigan

Established numerous business partnerships with organizations such as Meijer, K-Mart Pharmacies, Michigan Retailers Association, Michigan Grocers Association, and Pharma to promote the program and distribute applications, as well as partnering with the Michigan Association of Broadcasters to run some media spots free of charge.

Employed enrollment brokers to facilitate enrollment at one centralized processing site for all MIChild applications. Also, has State agency eligibility workers on site to process Healthy Kids applications and uses a special computerized program to help the broker-employee refer the applicant to the appropriate program.

New Jersey

Established innovative outreach partnerships with many State agencies, including innovations such as the Division of Motor Vehicles which mails KidCare materials with license and registration forms, and the Department of Health and Senior Services which provides birth registry data to the State's program and subsequently notifies new parents. Also, developed private partnerships with health care providers, agencies, and community-based organizations.

Established an extensive volunteer network, especially with the AmeriCorp VISTA volunteer project. VISTA volunteers actively work to identify uninsured children from low-income working families who may be eligible for the program. AmeriCorp has enabled the State to increase resources and strengthen its program in terms of cost effectiveness and efficiency.

New Mexico

Trained and out-stationed over 1,000 eligibility workers to enroll children presumptively and to assist families with the enrollment process.

Launched a statewide campaign emphasizing the multi-cultural diversity of the "New Mexikids" program through newspaper and radio spots in English, Spanish, and Navajo. Brochures, pencils, and magnets have been distributed through various health care providers, including all the Native American tribes.

Oklahoma

Enlisted partnerships with tribal leaders, community health centers, Head Start centers, WIC, Department of Health, and community action agencies. The CHIP application form was shortened from sixteen pages to one and the state eliminated the assets test.

Developed materials and implemented a culturally-sensitive training program to address culturally different groups and subpopulations.

South Carolina

Established extensive private partnerships with pharmacies, licensed day care centers, schools, and religious organizations throughout the State. These organizations distribute the CHIP mail-in applications.

Enhanced its relationship with Native Americans through discussions on the Catawba Indian reservations and with the March of Dimes to provide better services to and assist in enrolling the Native American population and the migrant and Hispanic populations, respectively.

Utah

Developed a community-level outreach program statewide with active staff participation.

Expanded the number of community partnerships to over 70 locations.

Question. How do these activities mesh with what research indicates are effective and ineffective outreach strategies for the targeted CHIP population?

Answer. A recent publication of the National Center for Education in Maternal and Child Health, titled "Successful Outreach Strategies: Ten Programs That Link Children to Health Services," indicates that "relatively little evaluation of outreach activities has been published in the literature." However, States are currently collecting data on these issues. Some States are including a section on their application which asks where the person heard about the program. Other States are coding certain applications to determine where the most are being distributed and completed, i.e., through the schools, through the hospitals, etc. Because many of these programs

are relatively young, States have yet to determine what strategies enroll the largest numbers of people.

Question. What are the per-eligible costs associated with effective outreach strategies?

Answer. HCFA has received some claims for Federal Financial Participation CHIP outreach from some States. However, while some of these costs are broken down into specific outreach activities, others are not. Associating costs with specific outreach activities is difficult. Outreach efforts are multi-faceted and individual decision making processes are complex making it difficult to determine which outreach activities and at which point in time the outreach activity prompted the decision to enroll. A person who decides to enroll may only do so after seeing a television ad, hearing about it on the radio, hearing other people talk about the program, seeing a poster, and then calling a toll-free number. Individuals may not enroll for several weeks or months after being exposed to outreach efforts.

There may be substantial start-up costs in creating new materials and identifying where efforts should be targeted, but outreach is really a long term investment. It is unclear how long specific outreach activities remain effective. Additionally, cost per eligible may vary depending on geographic area, specific population targeted, or a variety of other factors. CHIP programs are fairly new, and States have had insufficient time to evaluate the costs and effectiveness of outreach costs per eligible.

HCFA has provided cultural competency training to regional staff to assist States in working with community groups and other stakeholders to identify cost-effective strategies which facilitate enrollment into CHIP. Private sector partners are also working to create ways of assessing outreach strategies.

Measuring the effectiveness of states' outreach activities is critical to continual improvement of outreach efforts. HCFA is committed to assisting States in determining ways to measure successful and cost-effective outreach.

Question. What type of guidance has HCFA provided to states on these issues?

Answer. HCFA has conducted Regional Office outreach conferences, focus groups, technical advisory panels, and prepared a series of letters encouraging States to design and implement outreach activities that will reach the largely diverse groups of uninsured children. Formal guidance to States, offered through these letters, promote simplifying the enrollment process and developing innovative outreach practices.

For example, HCFA issued guidance to the States in a letter dated September 10, 1998, which highlighted opportunities for outreach and the flexibility States have to simplify the application and enrollment process. The letter offered clarification of two major eligibility-related issues that impact on enrollment: (1) the provision of Social Security numbers for applicants and non-applicant family members and (2) the establishment of immigration status for non-citizens.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Question. In its fiscal year 1999 funding request, Health Resources and Services Administration (HRSA) expressed a need to increase the supply of: primary care practitioners, geriatric faculty and geriatric trained practitioners, dentists with post-doctoral degrees, and public health professionals. Please explain what has happened in the last fiscal year to eliminate the need for funding this professional training, especially (a) primary care physicians who often serve as gatekeepers in the growing managed care environment; and (b) geriatric practitioners, in light of the "baby boom" factor.

Answer. The Department recognizes that primary care, post-doctoral dentistry, geriatric, and public health training is a critical need. However, there are also severe national needs in other areas. For these particular programs, the Department believes that other forces such as market demand, the Medicare program, the states, and educational institutions will provide resources for training of these health care providers.

Question. HRSA's fiscal year 2000 funding request for health professions emphasizes the need for more diversity in health care providers and to improve access to and quality of health care in underserved areas. Please provide information on other federal programs that encourage participation of ethnic minorities in health care.

Answer. In addition to the HRSA Health Professions activities, other departmental programs work to increase participation of minorities in the provision of health care.

HRSA's National Health Service Corps (NHSC) is a primary care, safety-net program which recruits and places clinicians in underserved communities, including inner city and rural areas where primary heath care programs are often difficult to access. The NHSC Recruitment program, which includes scholarship and loan re-

payment activities, recruits its recipients from diverse ethnic and cultural backgrounds. For the 326 fiscal year 1998 scholarship awardees, 43 percent were minority clinicians (19 percent African American, 8 percent Hispanic, 7 percent Asian, 0.1 percent American Indian and 9 percent other). For the 521 fiscal year 1998 Federal Loan Repayment recipients, 33 percent were minority clinicians (19 percent African American, 9 percent Hispanic, 4 percent Asian, 1 percent Native American and 0.4 percent Pacific Islander). The percentage of NHSC providers from underrepresented minority backgrounds exceeds those of the Nation's health workforce and even exceeds the percentage of these individuals that comprise the Nation's population. The NHSC maintains a strong commitment to recruiting a diverse provider base. The fiscal year 2000 budget proposes $115 million for NHSC activities.

The Indian Health Service (IHS) provides health professions scholarships for Native American students both to increase the number of Indian health professionals and to assure an adequate number of health professionals are available to meet the needs of the IHS and other organizations providing health care for Indian people. Approximately 600 students are supported annually. Scholarships are provided for attendance at professionals school (e.g., medicine, nursing) and for necessary preprofessional education (e.g., pre-medicine, or pre-dentistry). Students receiving scholarships for professional school incur a service obligation which they can discharge either by working for the IHS, working for tribal or urban Indian organizations receiving IHS funds, or practicing in health professions shortage areas serving substantial numbers of Indian people. The fiscal year 2000 budget request includes approximately $14 million for the scholarship program.

Question. Does the need for more diversity and service in underserved areas come at the expense of diversity in other more adequately served areas?

Answer. Increasing diversity of the health professions workforce in underserved areas is not expected to come at the expense of diversity in more adequately served areas. More diversity in the health professions workforce is needed throughout the country. Currently, minorities constitute 25 percent of the total population but only 10 percent of the health care workforce. Even with HRSA training funds and the various strategies HRSA employs for improving the diversity of the health professions workforce, minorities in the health professions are not keeping pace with minority population growth. It should be noted that studies have shown that minority health professionals are more likely to locate in underserved areas and provide services to ethnic populations. Thus, diversifying the health professions workforce improves access to health care for underserved populations.

HIV AND MINORITIES

Question. What specific projects and programs are planned at HRSA, CDC, and SAMSHA to address the problem of HIV/AIDS in racial and ethnic communities?

Answer. For fiscal year 1999, the U.S. Department of Health and Human Services will spend $156 million to enhance the Federal response to HIV/AIDS in racial and ethnic minority communities. Of these funds, $144 million will be administered by HRSA, CDC, and SAMHSA. This funding is spread across three broad categories: technical assistance and infrastructure support; increasing access to prevention and care, and building stronger linkages to address the needs of specific populations.

The specific Initiative projects and programs planned at HRSA, CDC and SAMHSA include:

Health Resources and Services Administration (HRSA)

Targeted Provider Education ($2.8 million).—This initiative will target providers serving racial and ethnic minority populations at high risk within defined service areas—adolescent medicine, prison medicine providers, juvenile correctional facilities, homeless shelters, drug treatment, family planning providers, and OB/GYNs. It will also improve the capacity of minority providers/institutions to directly provide assistance, care and services through telemedicine and related efforts.

Peer Education Community Training Institute ($2.0 million).—This program will support the training and development of knowledgeable peer educators to work within their minority communities on treatment education, to increase the awareness, acceptance and appropriate utilization of effective new therapies among HIV-infected persons.

Capacity Building Demonstration Project ($1.0 million).—This investment expands a multi-city demonstration project focused on outreach to minority community-based organizations not already receiving federal dollars. It assists CBOs to develop and maintain linkages with other service sites to complete the continuum of medical care and support services needed for HIV infected minority populations, and to improve their ability to receive and retain federal grants and diversity their financial support to improve stability.

Title IV Programs of the Ryan White CARE Act ($12.2 million).—To support care and access to research for children, women, youth and families impacted by HIV/AIDS. More than two-thirds of this program's clients are African-American or Hispanic. This program was continued from fiscal year 1998.

Integrated Services/Ryan White Special Projects of National Significance ($135,000).—Continued funding from fiscal year 1998 for a project developing models of care linking HIV ambulatory care with mental health, substance abuse treatment and other important HIV-related services targeting African-Americans and Latinos in the Los Angeles area.

Help for CBOs ($100,000).—To develop and pilot test a training program for minority CBOs in three cities by April 1999, continuing funding from fiscal year 1998.

Healthy Start ($950,000).—These funds will be used to meet a new requirement of the Healthy Start program that says all Healthy Start projects conduct HIV/AIDs related activities for about 1 million childbearing-age African-American women in Healthy Start communities, including outreach, screening and counseling.

Community Health Centers Service Delivery ($1.0 million).—Also continued from fiscal year 1998, this is designed to provide innovative outreach and primary care services in heavily impacted racial and ethnic minority communities.

Ryan White Title I Emergency ($5.0 million).—This supplemental funding from Congress is going to eligible metropolitan areas with more than 30 percent African-American and Latino HIV/AIDS cases to improve the quality of care and health outcomes.

Ryan White Title III Planning Grants ($3.0 million).—These grants help community- based organizations located in medically underserved areas (both rural and urban) plan primary care services for African-American communities heavily impacted by HIV/AIDS.

Ryan White AIDS Education and Training Centers ($2.0 million).—This will provide Historically Black Colleges and Universities support for training minority providers in up-to-date treatment standards for persons with HIV/AIDS.

Centers for Disease Control and Prevention (CDC)

Technical Assistance and Capacity Development ($5.0 million, CDC, HRSA, NIH, SAMHSA, and OPHS).—These funds will be invested in new approaches to delivering technical assistance and nurturing the development of service delivery capacity within minority communities in need of HIV prevention and treatment services.

Community Development Grants for HIV/STD/TB/Substance Abuse/Integration/Linkages ($4.0 million, CDC with HRSA and SAMHSA).—These grants will go to local communities to support needs assessments and planning processes to integrate HIV, STD, TB and substance abuse prevention and care.

HIV Prevention Among Gay Men of Color ($7.0 million).—These funds will support HIV prevention organizations serving gay men of color for the delivery of heath education, outreach, counseling and testing, prevention case management and formal referral to services. Technical assistance will also be provided to support a durable capacity to deliver effective prevention interventions and services

Linkages of Incarcerated Populations with Community Prevention and Care ($5.0 million).—Funds will support collaborative demonstration and service enhancement projects to develop discharge planning/community integration models for prevention case management for HIV-infected inmates upon release, facilitate formal linkages into care upon discharge, and ensure continuation of ongoing HIV medical therapies during transition to community-based care.

Prevention Education and Early Identification Project ($6.2 million, CDC and NIH with HRSA and SAMHSA).—These funds will support the development of new and innovative early identification strategies to reach high risk populations and create linkages with care, with a focus on adolescents and women of color.

Minority Community-Based Organizations (CBO) and Prevention ($4.0 million).—This continues fiscal year 1998 competitive funding, through state and Local health departments, for racial and ethnic minority CBOs in 30 high-priority areas for HIV prevention in African-American and Latino communities.

Prevention Among HIV Positive Persons ($3.9 million).—To continue fiscal year 1998 funding for five HIV prevention demonstration projects, especially for racial and ethnic minorities and others that have a tough time accessing treatment and prevention services.

HIV Prevention Through STD Treatment ($1.7 million).—Continued funding from fiscal year 1998 for enhanced syphilis elimination efforts in 13 areas heavily impacted by the disease. Syphilis disproportionately impacts communities of color and early STD detection and treatment reduces the risk of HIV transmission.

Prevention for Gay Men ($800,000).—Continued funding from fiscal year 1998 for universities and organizations to conduct behavioral research on the effectiveness of

HIV prevention interventions for gay men, especially racial and ethnic minorities. Also for testing new interventions.

Reducing Transmission ($400,000).—Continued from fiscal year 1998, these funds will help CDC develop population-specific strategies to better target prevention resources and help CBOs expand their ability to provide effective interventions.

Better Targeting of Community Prevention Funding ($15.0 million).—CDC will work with states to make HIV Prevention Community Planning allocation decisions reflective of their HIV demographics, and will use the funding for redirection to African-American and Latino communities as necessary.

Directly Funded CBOs ($10.0 million).—For direct funding of grant applications of indigenous organizations with a history of working with African-American communities to target high-risk populations.

Technical Assistance ($2.5 million).—For national, regional and Local minority organizations to provide technical assistance to minority CBOs that are in the direct funding program.

Faith Based Initiatives ($1.5 million).—For developing HIV and substance abuse prevention programs at divinity schools located at Historically Black Colleges and Universities, and for expanding the ability of other faith-centered programs in this area.

Community Development ($4.0 million). To be used to create new community development grants for African-American areas heavily impacted by HIV/AIDS that will lead to the integration of HIV/AIDS, STD, TB, and substance abuse prevention, treatment and care in these communities.

Pilot Prison Programs ($2.5 million).—These funds will be used to work with state and Local corrections officials to track the impact of HIV/AIDS within prisons, guide effective prevention and treatment interventions, and help link those about to be released to sources for community-based care.

HIV-Positive Research and Prevention Models in Minority Communities ($1.0 million).—To start research projects that evaluate innovative prevention interventions for HIV-positive African-American women and their sex partners. This will complement existing CDC research on developing interventions for HIV-positive men. In addition, CDC's $10 million demonstration program eliminating racial and ethnic health disparities will fund approximately 30 sites to develop community action plans designed to identify and implement effective interventions aimed at improving health disparities in racial and ethnic populations. HIV/AIDS is one of the six health disparities targeted by the Departmental Initiative.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Outreach Grants ($7.5 million, SAMHSA/CSAT).—These grants will support substance abuse outreach workers in African American and Hispanic communities in those cities with high HIV/AIDS case rates, increasing HIV testing outreach and formal linkages with both substance abuse treatment and HIV prevention and care.

Substance Abuse Prevention/HIV Care Capacity Grants ($5.0 million, SAMHSA/CSAP).—These grants will fund substance abuse treatment programs that want to expand their HIV expertise, and those HIV care programs that want to offer substance abuse services.

Programs for Women and Children ($9.0 million).—The Congress has directed that $9 million be used for comprehensive treatment for women and their children.

Substance Abuse Treatment for Men ($7.0 million).—In addition to targeted programs for women and children, the Congress has directed an additional $7 million to support substance abuse treatment programs that include an HIV component.

Center for Substance Abuse Prevention ($8.5 million).—The Congress has directed an additional $6 million to complement $2.5 million in the President's budget request to be targeted to prevention services for African American and Hispanic youth.

Setaside for Linkages with HIV Services ($2.5 million).—Establish linkages between substance abuse treatment and HIV services within SAMHSA's new Targeted Capacity Expansion initiative, and place an earmark of $2.5 million within the program next year for an integrated substance abuse and HIV care component.

Question. Which HHS agencies have received portions of the $50 million amount in the Office of the Secretary of HHS and what projects and programs will these funds be supporting?

Answer. The Public Health and Social Services Emergency Fund (PHSSEF) includes $50 million to address the HIV/AIDS crisis in racial and ethnic minority communities through specifically targeted programs that respond to the changing demographics of the disease. These funds will be used for high priority prevention and treatment needs in areas heavily impacted by HIV/AIDS and will complement existing and previously planned targeted HIV/AIDS activities regarding communities of

color. Initiatives to be supported with these resources include the following activities (with lead agency noted):

Outreach Grants ($7.5 million, SAMHSA/CSAT).—These grants will support substance abuse outreach workers in African American and Hispanic communities in those cities with high HIV/AIDS case rates, increasing HIV testing outreach and formal linkages with both substance abuse treatment and HIV prevention and care.

Substance Abuse Prevention/HIV Care Capacity Grants ($5.0 million, SAMHSA/CSAP).—These grants will fund substance abuse treatment programs that want to expand their HIV expertise, and those HIV care programs that want to offer substance abuse services.

Community Development Grants for HIV/STD/TB/Substance Abuse/Integration/Linkages ($4.0 million, CDC with HRSA and SAMHSA).—These grants will go to local communities to support needs assessments and planning processes to integrate HIV, STD, TB and substance abuse prevention and care.

HIV Prevention Among Gay Men of Color ($7.0 million, CDC).—These funds will support HIV prevention organizations serving gay men of color for the delivery of heath education, outreach, counseling and testing, prevention case management and formal referral to services. Technical assistance will also be provided to support a durable capacity to deliver effective prevention interventions and services

Linkages of Incarcerated Populations with Community Prevention and Care ($5.0 million, CDC).—Funds will support collaborative demonstration and service enhancement projects to develop discharge planning/community integration models for prevention case management for HIV-infected inmates upon release, facilitate formal linkages into care upon discharge, and ensure continuation of ongoing HIV medical therapies during transition to community-based care.

Prevention Education and Early Identification Project ($6.2 million, CDC and NIH with HRSA and SAMHSA).—These funds will support the development of new and innovative early identification strategies to reach high risk populations and create linkages with care, with a focus on adolescents and women of color.

Targeted Provider Education ($2.8 million, HRSA).—This initiative will target providers serving racial and ethnic minority populations at high risk within defined service areas—adolescent medicine, prison medicine providers, juvenile correctional facilities, homeless shelters, drug treatment, family planning providers, and OB/GYNs. It will also improve the capacity of minority providers/institutions to directly provide assistance, care and services through telemedicine and related efforts.

Peer Education Community Training Institute ($2.0 million, HRSA).—This program will support the training and development of knowledgeable peer educators to work within their minority communities on treatment education, to increase the awareness, acceptance and appropriate utilization of effective new therapies among HIV-infected persons.

Provider/Peer Education Project Through Telecommunications ($1.5 million, NIH).—This initiative supports the utilization of Internet technologies within minority community-based organizations to make available up-to-date information, multimedia presentations, re-broadcasts of treatment education and adherence curriculum sessions, and serve as centralized resource for treatment information publications and conferences.

Capacity Building Demonstration Project ($1.0 million, HRSA).—This investment expands a multi-city demonstration project focused on outreach to minority community-based organizations not already receiving federal dollars. It assists CBOs to develop and maintain linkages with other service sites to complete the continuum of medical care and support services needed for HIV infected minority populations, and to improve their ability to receive and retain federal grants and diversity their financial support to improve stability.

Community Leadership Development ($3.0 million, OPHS).—These funds will supplement the Minority Community Health Coalition Grants administered by the Office of Minority Health, and support an initiative in partnership with the leadership of a broad spectrum of minority business, civic, and professional associations/organizations to develop effective strategies to engage all sectors of local communities to address HIV/AIDS in minority communities.

Technical Assistance and Capacity Development ($5.0 million, CDC, HRSA, NIH, SAMHSA, and OPHS).—These funds will be invested in new approaches to delivering technical assistance and nurturing the development of service delivery capacity within minority communities in need of HIV prevention and treatment services.

Question. What plans have been made for the $54 million contained in the HHS fiscal year 1999 budget? Describe the $24 million in continuing activities begun in fiscal year 1998, and the $30 million in new fiscal year 1999 activities.

Answer. Of the $55.5 million included in the fiscal year 1999 President's Budget as part of the Administration's Initiative to address HIV/AIDS among racial and

ethnic minority populations, $25 million will continue activities begun in fiscal year 1998 and $30.5 million will support new activities. The activities supported are described below:

CONTINUING ACTIVITIES

Centers for Disease Control and Prevention (CDC)

Minority Community-Based Organizations (CBO) and Prevention ($4.0 million).—This continues fiscal year 1998 competitive funding, through state and Local health departments, for racial and ethnic minority CBOs in 30 high-priority areas for HIV prevention in African-American and Latino communities.

Prevention Among HIV Positive Persons ($3.9 million).—To continue fiscal year 1998 funding for five HIV prevention demonstration projects, especially for racial and ethnic minorities and others that have a tough time accessing treatment and prevention services.

HIV Prevention Through STD Treatment ($1.7 million).—Continued funding from fiscal year 1998 for enhanced syphilis elimination efforts in 13 areas heavily impacted by the disease. Syphilis disproportionately impacts communities of color and early STD detection and treatment reduces the risk of HIV transmission.

Prevention for Gay Men ($800,000).—Continued funding from fiscal year 1998 for universities and organizations to conduct behavioral research on the effectiveness of HIV prevention interventions for gay men, especially racial and ethnic minorities. Also for testing new interventions.

Reducing Transmission ($400,000).—Continued from fiscal year 1998, these funds will help CDC develop population-specific strategies to better target prevention resources and help CBOs expand their ability to provide effective interventions.

Health Resources and Services Administration (HRSA)

Title IV Programs of the Ryan White CARE Act ($10.2 million).—To support care and access to research for children, women, youth and families impacted by HIV/AIDS. More than two-thirds of this program's clients are African-American or Hispanic. This program was continued from fiscal year 1998.

Integrated Services/Ryan White Special Projects of National Significance ($135,000).—Continued funding from fiscal year 1998 for a project developing models of care linking HIV ambulatory care with mental health, substance abuse treatment and other important HIV-related services targeting African-Americans and Latinos in the Los Angeles area.

Help for CBOs ($100,000).—To develop and pilot test a training program for minority CBOs in three cities by April 1999, continuing funding from fiscal year 1998.

Healthy Start ($950,000).—These funds will be used to meet a new requirement of the continuing Healthy Start program that states all Healthy Start projects conduct HIV/AIDs related activities for about 1 million childbearing-age African-American women in Healthy Start communities, including outreach, screening and counseling.

Community Health Centers Service Delivery ($1.0 million).—Also continued from fiscal year 1998, this is designed to provide innovative outreach and primary care services in heavily impacted racial and ethnic minority communities.

Office of Minority Health (OMH)

Minority Community Coalition Demonstration Grants ($748,225).—Funding for this program was awarded in fiscal year 1999 to continue work begun through five grants in fiscal year 1998 to implement health education and outreach programs to reduce risk factors for HlV/AlDS transmission in minority communities.

Bilingual/Bicultural Demonstration Grants ($500,000).—The Office of Minority Health received $500,000 in fiscal year 1999 to continue its work from fiscal year 1998 on projects to increase access to bilingual/bicultural HIV/AIDS education and prevention services for racial/ethnic minority populations.

Office of Minority Health Resource Center ($341,000).—Funding for fiscal year 1999 will allow this center to continue providing the public with information and technical assistance on issues affecting the health of racial and ethnic minority populations. The centers database of minority health information, including HIV/AIDS information, is accessible through a toll-free telephone line (with Spanish and English-speaking information specialists) or a site on the World Wide Web.

National Minority AIDS Council ($100,000).—To maintain the continued cooperative agreement between the Office of Minority Health and the Council, fiscal year 1999 funding was appropriated. In fiscal year 1998, the office of Minority Health provided $100,000 to: (1) cosponsor the U.S. Conference on AIDS; (2) disseminate and share information related to the National Minority HIV Plan, and (3) develop and conduct a one year national educational campaign on protease inhibitors.

NEW ACTIVITIES

Centers for Disease Control and Prevention (CDC)

Better Targeting of Community Prevention Funding ($15.0 million).—CDC will work with states to make HIV Prevention Community Planning allocation decisions reflective of their HIV demographics, and will use the funding for redirection to African-American and Latino communities as necessary.

Pilot Prison Programs ($2.5 million).—These funds will be used to work with state and Local corrections officials to track the impact of HIV/AIDS within prisons, guide effective prevention and treatment interventions, and help link those about to be released to sources for community-based care.

HIV-Positive Research and Prevention Models in Minority Communities ($1.0 million).—To start research projects that evaluate innovative prevention interventions for HIV-positive African-American women and their sex partners. This will complement existing CDC research on developing interventions for HIV-positive men.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Center for Substance Abuse Prevention ($2.5 million).—The Congress has directed an additional $6 million to complement $2.5 million in the President's budget request to be targeted to prevention services for African American and Hispanic youth.

Setaside for Linkages with HIV Services ($2.5 million).—Establish linkages between substance abuse treatment and HIV services within SAMHSA's new Targeted Capacity Expansion initiative, and place an earmark of $2.5 million within the program next year for an integrated substance abuse and HIV care component.

National Institutes of Health (NIH)

Research Initiatives ($7.0 million).—These funds will be used to diversify HIV/AIDS research involving communities of color, including raising the number of African-American and Hispanic principal investigators in HIV behavioral and clinical research, providing outreach education to minority physicians and at-risk populations, and expanding population-based research on African-Americans and Hispanics.

Question. What projects and programs are planned for the territories, such as the Virgin Islands, where the HIV/AIDS case rate is "more than twice the national case rate?"

Answer. The Department have been in dialogue with Delegate Donna Christensen to discuss the impact of HIV/AIDS on the population of the Virgin Islands, and strategies to effectively address the unique challenges it presents. The Virgin Islands had the third highest AIDS case rate among the states and territories for the period of July 1997 to June 1998, with a cumulative total of 393 AIDS cases reported since the institution of AIDS surveillance. Among the Department's fiscal year 1999 activities, the Centers for Disease has set aside $500,000 in fiscal year 1999 for HIV prevention efforts in the U.S. Virgin Islands. The Office of AIDS Research in the National Institutes of Health is also exploring setting up a training meeting in the Virgin Islands provide treatment updates and cutting edge information to physicians and other health care providers. In other areas, these meetings have been the beginning of identifying a base of providers serving the HIV-affected population and nurturing the development of future research interests. The Health Resources and Services Administration has been supporting HIV/AIDS provider education in the Virgin Islands through the AIDS Education and Training Program (AETC) grant awarded the New York Region. Through additional resources provided by the Congress in fiscal year 1999, the AETC program will be developing new partnerships with Historically Black Colleges and Universities for these activities.

BIOTERRORISM PREPARATION

Question. Would you explain how the Department is progressing with its bioterrorism preparedness effort?

Answer. In this, the first year of the DHHS anti-Bioterrorism initiative, the Department has launched the implementation of several activities. The fiscal year 1999 Anti-Bioterrorism Operating Plan, developed in concert with the Centers for Disease Control and Prevention (CDC), the Office of Emergency Preparedness (OEP) and the National Institutes of Health (NIH), was submitted to Congress outlining a variety of activities that would be undertaken this fiscal year.

With respect to the funds provided to CDC for surveillance and the pharmaceutical stockpile, we are pleased to report that CDC has already prepared and released a Program Announcement to state health departments inviting them to apply for funds to initiate planning and implementation of several anti-bioterrorism activi-

ties. These funds, to be awarded as cooperative agreements, focus on five separate areas, for which a state health department could apply for one or several. These five focal areas are: State Preparedness Planning and Readiness Assessment; Surveillance and Epidemiology Capacity; Laboratory Capacity-Biologic Agents; Laboratory Capacity-Chemical Agents; and the Health Alert Network. A total of approximately $41 million will be available to fund cooperative agreements in these areas, broken down as follows:

[In millions of dollars]

Preparedness Planning and Readiness Assessment	1.3
Surveillance and Epidemiology Capacity	7.88
Laboratory Capacity-Biologic Agents	8.8
Laboratory Capacity-Chemical Agents	4
Health Alert Network	19

With respect to the stockpile, CDC has established a branch within the National Center for Environmental Health with specific responsibility to plan for and manage the stockpile and associated activities. These would include the purchase, storage and delivery of pharmaceuticals, supplies and equipment. CDC is working closely with OEP on threat assessment; treatment protocols for the threats identified; phased-in procurement of stockpile items, by priority; and delivery and distribution mechanisms for contents of the stockpile. CDC will also engage in dialogues with DOD and DVA to discuss mechanisms for procurement, storage and shipment of stockpile items. Furthermore, there are a number of issues that are being reviewed and assessed so that informed decisions can be made, e.g., exact locations of various stockpile items; what constitutes a "trigger" event that would result in deployment of stockpile contents; long term care of victims of a bioweapons attack, etc.

The Office of Emergency Preparedness has also embarked on a number of activities with respect to enhancing medical and public health consequence management at the local level. To date OEP has already contracted with 27 cities to develop Metropolitan Medical Response Systems (MMRS). In fiscal year 1999, HHS will initiate another 20 city systems.

OEP is also increasing the size of the deployable National Medical Response Teams (NMRTs) from 24 to 48 individuals per team to ensure a robust response to either chemical or biological terrorist attacks. The amount of specialized pharmaceuticals for each team will be significantly augmented so that each team will have the capacity to treat up to 5,000 victims (an increase from the current maximum of 1,000).

OEP will continue to deploy, exercise and train in a multi-agency setting with the Departments of State, Defense, and Energy, FBI, EPA and state and local governments to ensure a coordinated medical response. It is also OEP that will detail personnel to staff the health and medical section of the recently established National Domestic Preparedness Office in the FBI.

Question. What is CDC's role in this initiative? How many states are currently involved? Do you plan to collaborate with all the states? If so, how long will that take?

Answer. The role of the Centers for Disease Control and Prevention (CDC) in the bioterrorism initiative is to develop the Nation's ability to detect and respond to a silent bioterrorist attack, and lead the public health response in the event of a terrorist attack that involves biological or chemical agents. To this end the CDC is intensifying its efforts to upgrade the nation's public health laboratory, epidemiology and surveillance capacities. CDC is also expanding training and communication capacities for State and local health agencies.

Presently, CDC is working with the Association of State and Territorial Health Officers (ASTHO) and the National Association of City and County Health Officers (NACCHO) on issues related to the infrastructure needs of the State and local health departments in order to assure that the health communities are able to conduct an immediate, efficient and effective response to a biological or chemical terrorist attack. On an ongoing basis, CDC provides direct technical assistance around issues of laboratory testing and methods, epidemiology and surveillance, and program development and support to the nation's public and private health community through site visits, consultation, training and educational presentations. In addition, on February 26, 1999, a request for applications was provided to 62 State, local and territorial health agencies. The approximate amount of funding available is $41,000,000. The purpose of these funds is to assist successful applicants in the areas of: (1) preparedness planning and readiness assessment, (2) enhanced surveillance and epidemiology capacity, (3) expanded laboratory capacity for biological and

chemical agents, and (4) the development of a Health Alert Network. Funding will be awarded through cooperative agreement in mid-August 1999.

Question. How do HHS activities mesh with the anti-bioterrorism efforts of other agencies, such as the Department of Justice, Department of Defense, and the Federal Emergency Management Agency?

Answer. HHS is the lead Federal agency with responsibility for health and medical consequence management for terrorist attacks and natural disasters, under the Federal Response Plan managed by FEMA and PDD–62. The Department seeks to develop complementary medical response capabilities at local and national levels. HHS works closely with other agencies especially the relevant components of the Departments of Justice (DOJ), Department of Defense (DOD), Department of Veterans Affairs (VA), and the Federal Emergency Management Agency (FEMA)—to ensure that plans for managing the medical consequences of terrorist acts are well integrated with our emergency response systems. The Department has used an interagency review process to review contracts related to some of our bioterrorism initiatives.

Question. How long do you think it will take for this country to complete its bioterrorism preparedness effort?

Answer. Speaking for the civilian sector and within the medical and public health parameters, it is impossible to provide a definitive response to this question. After the first three to five years of implementation of the anti-bioterrorism strategy that DHHS has articulated in both the fiscal year 1999 Operating Plan and in the Justification of fiscal year 2000 Estimates for the Appropriations Committees, will be in a better position to assess what has been accomplished so far and what remains to be done.

PUBLIC HEALTH INFRASTRUCTURE

The President proposes that an additional $94 million be appropriated to fund these public infrastructure activities.

Question. What resources are being contributed by states and the private sector to strengthen the public health infrastructure?

Answer. The $94 million you mention is aimed at strengthening science for public health action. It includes $22 million to construct needed laboratories at CDC, $15 million to improve health statistics, and $12 million to support the National Occupational Research Agenda., and $45 million for the public health surveillance initiative which includes food safety, hepatitis C, emerging infectious diseases, and bioterrorism surveillance. This $94 million is supplemented by an additional $20 million for bioterrorism surveillance requested through the Public Health and Social Services Emergency Fund.

Although most of these specific initiatives do not require additional contributions by the States, many of CDC's programs depend on state and local governments and private organizations. For example:

States and local governments participate in cooperative agreement programs aimed at infectious disease. The average State in-kind contribution for the Emerging Infections Program (EIP) is approximately $233,000. California has put an additional $1.955 million in next year's budget for emerging infectious diseases and food safety activities.

Nearly all immunization grantees provide support at some level. In 1998, South Carolina contributed $4.8 million to supplement immunization program operations and purchased vaccine totaling $2.3 million. California contributes about $3.5 million dollars annually to support growth and development of local and regional immunization registries and to enhance public-private partnerships to improve preschool immunization levels.

Many of the chronic disease prevention programs require State matching funds. For instance, the National Breast and Cervical Cancer Early Detection Program and the National Program of Cancer Registries require States to provide $1 for each of $3 Federal funds provided.

Question. Realistically, what will happen if these activities are not funded at the full proposed levels?

Answer. These increases are needed to move us toward the public health system we will need for the 21st century. Without the lab funding, scientists would have to continue using World War II barracks for labs. Without the bioterrorism surveillance funding, we will continue having an inadequate network of State/major metro area laboratories for early identification and characterization of disease outbreaks, and will not be able to establish an Emergency Response Unit to provide rapid field assessments in the event of a suspected release of a biological agent. The food safety funding is needed to expand DNA fingerprinting to additional pathogens, to speed

up responses to food borne disease outbreaks. Without the emerging infectious disease funding, CDC could not provide financial and technical assistance to 10 State and large local health departments for enhanced surveillance and response to emerging diseases. Without the Hepatitis C funding, CDC would have a more limited HCV information and education campaign, and demonstration projects in select high prevalence States or major cities would not be initiated. Without the health statistics funding, CDC could not help States implement a major revision to the international coding system for mortality, or assist States in moving to electronic systems that will improve quality and timeliness. Without the funding for the National Occupational Research Agenda (NORA), there will be inadequate research on what needs to be done to control occupational hazards causing illness, injury, death, and their related economic and social burden.

Question. Would you describe how the national hepatitis C public information campaign will operate.

Answer. The National Hepatitis C Public Information Campaign will consist of a multi-layered campaign of both media and public education materials that seek to raise awareness of the potential seriousness of HCV infection; educate persons transfused before 1992 that they are at risk of infection and should be tested; and motivate transfusion recipients to seek testing and medical follow-up if infected. This campaign will be launched in early May 1999 with a media briefing, which will be followed by both print and radio public service announcements (PSAs), consumer outreach material for health providers, press releases, fact sheets, media copy, story ideas for magazines and TV, and public transit advertisements (PSAs). In addition, patient groups likely to have been transfused, health care professionals who care for such patients, voluntary health organizations/patient advocacy groups will be invited to a series of regional workshops which will provide education about the risk of transfusion-acquired HCV infection, and which will also encourage and facilitate the identification and testing of persons who might have acquired hepatitis C from a transfusion.

TOBACCO ISSUES

Proposed increase in federal cigarette excise tax

The President's fiscal year 2000 budget calls for a 55 cents-a-pack increase in the Federal cigarette excise tax to "offset tobacco-related Federal health care costs." Under the Balanced Budget Act of 1997 (BBA: Public Law 105–33), the current Federal excise tax of 24 cents per pack is already set to increase by 10 cents on January 1, 2000, and an additional 5 cents on January 1, 2002. The fiscal year 2000 budget proposes that the full 15-cents increase take effect on January 1, 2000. The excise tax proposals in the fiscal year 2000 budget would generate estimated receipts of $8 billion in fiscal year 2000, decreasing to $6.4 billion in fiscal year 2004.

The fiscal year 2000 budget estimates that tobacco-related health care will cost DOD, VA, the Indian Health Service, and the Federal Employees Health Benefits Program $8.0 billion in fiscal year 2000, increasing to $8.9 billion in fiscal year 2004.

Question. Precisely how does the Administration propose to spend these additional cigarette tax revenues?

Answer. Tobacco-related health problems cost the Federal government billions of dollars each year. In the case of tobacco, the Administration is seeking reimbursement to the taxpayer for costs directly attributable to the tobacco companies. Exclusive of Medicaid and Medicare, the Administration has calculated the annual tobacco-related health care costs in fiscal year 2000 for four major Federal programs. These include Veterans Affairs ($4.0 billion), the Federal Employees Health Benefit program ($2.2 billion), Defense ($1.6 billion), and the Indian Health Service ($0.3 billion).

Question. Is the revenue from the 1997 BBA tax increase already earmarked, and if so, for what?

Answer. Current tobacco taxes are deposited in the general fund. The increases enacted in the 1997 BBA were used to help Congress and the Administration meet the overall deficit elimination goals, while also financing selected tax cuts and mandatory program improvements, such as the new Children's Health Insurance Program.

Question. How much of the Federal cost of tobacco related health care is already compensated by current or scheduled taxes?

Answer. The current excise taxes on tobacco products were neither designed nor intended to compensate the Federal government for such costs. Similarly, the excise taxes that States receive were not a factor in the recent Multistate Settlement

Agreement. That agreement recognized that those taxes were not designed nor intended to compensate the States for health care costs.

FEDERAL MEDICAID REIMBURSEMENT

Background

The Medicaid statute requires states to reimburse the Federal government for its share of any Medicaid expenditures that states recover from liable third parties.[1] Overall, HCFA pays about 57 percent of total Medicaid benefits spending. State Governors and attorneys general are strongly opposed to any efforts by HCFA to recover a portion of the Master Settlement Agreement (MSA) payments, arguing that the states brought the lawsuits against the industry without any Federal assistance and are entitled to all the funds awarded in the settlement. The National Governors Association (NGA) supports a bipartisan Senate bill introduced by Senator Hutchison (S. 346), which would prohibit Federal recoupment of MSA funds. The Administration opposes S. 346 because it lacks any guarantee that the funds will be used for tobacco-control and other public health programs. The President's fiscal year 2000 budget includes a 5 year projection of HCFA recoupment of MSA funds, starting at $4.6 billion in fiscal year 2001 and increasing to $4.8 billion in fiscal year 2004.[2]

Question. Are you willing to allow the states to keep all the MSA funds, and if so, under what conditions?

Answer. The President has made very clear the Administration's desire to work with Congress and the States to enact legislation that resolves the Federal claim in exchange for a commitment by the States to use that portion of the settlement for shared priorities which reduce youth smoking, protect tobacco farmers, assist children and promote public health.

Question. Is it reasonable to expect states to agree to restrictions on how they spend the money?

Answer. Under current law, States are required to pay these amounts to the Federal government. The President recommends allowing States to keep these funds, instead of remitting them, in exchange for a commitment by the States to use that portion of the settlement for shared priorities.

Several states are already pouring millions of dollars into tobacco-control programs. Some of them are using state cigarette tax revenues to fund the programs (e.g., CA, MA, AZ), while others are receiving individual settlement payments from the industry (e.g., MS, FL, TX, MN). Perhaps as early as this summer, 46 states will begin to receive MSA funds.

Question. Is the HHS (e.g., CDC) providing assistance to states such as Florida and California, which are already spending millions of dollars on anti-tobacco activities, to help them design and implement effective tobacco-control policies?

Answer. Yes, all States that have received dramatic infusions of funding for tobacco prevention and control in recent years have received in-depth technical assistance from CDC. In 1998, the four settlement States—Florida, Minnesota, Mississippi, and Texas—received in-depth technical assistance. At the State's request, CDC assisted Florida in every aspect of setting its primary program goals and building its infrastructure to implement the $200 million pilot program. At the State's request, CDC began working with Mississippi in July 1997, when the State settled with the tobacco industry. Consultation on evaluation have intensified since 1997 and several critical elements developed for the Florida pilot program evaluation were quickly disseminated to Mississippi. When Texas settled in January 1998, CDC brought the Texas Department of Health staff into the consultation loop with Mississippi and Florida. All aspects of the planning program implementation and evaluation were rapidly transferred to Texas. Minnesota settled its case in May

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[1] The Medicaid statute establishes that it is the state's responsibility "to ascertain the legal liability of third parties * * * to pay for care and services available under the [state's Medicaid] plan." Under the statute, states are authorized to pursue through the courts third party recoveries and provide the Federal government with its share of any recovered funds (Sections 1902(aX25) and 1903(d) of the Social Security Act). The Federal Government is not authorized by the Medicaid statute to sue third parties directly.

[2] These estimates represent approximately 57 percent of the total annual payments to the states, before any of the adjustments, reductions, or offsets. Determining the specific portion of each state's MSA payment that reflects Medicaid reimbursement for treating smoking-related illnesses would be extremely complex. Although the state tobacco lawsuits were widely seen as an attempt to recover smoking-related Medicaid costs, states used a variety of legal approaches to sue the industry. In many cases, Medicaid claims were only one component of states' lawsuits. Non-Medicaid recoveries (e.g., damages and penalties for violations of state antitrust and consumer protection laws) would not be subject to any Federal share requirements under the Medicaid statute.

1998. Minnesota Department of Health staff had been working with CDC prior to the settlement to harmonize multiple State tobacco control plans developed by State coalitions and advisory committees. The Minnesota Partnership for Action Against Tobacco, Tobacco Workgroup of the Minnesota Health Improvement Partnership, and the Minnesota Blue Cross Blue Shield are planning a comprehensive statewide tobacco prevention and control program. The timing, structure, and technical quality of the new programs funded by State settlements will be highly dependent upon the national leadership, coordination and technical assistance efforts supported by CDC.

Question. Does HHS plan to develop a national strategy to tie together the tobacco-control efforts of all the states?

Answer. In fiscal year 1999, CDC is funding all 50 States, the District of Columbia, and the territories, for core tobacco control programs, thereby establishing the National Tobacco Control Program. This program combines the 32 States and the District of Columbia funded through CDC with States previously funded by the National Cancer Institute. A nationwide tobacco control system will allow for coordination of State and Federal efforts:

Diffusion of information on "best practices" in tobacco control and prevention;

Build and expand upon CDC's current efforts with States;

Put in place programs that work, and achieve economies of scale; and

Evaluate outcomes to ensure that tobacco control provides a good return on investment, and that Federal government and States are held accountable for positive outcomes.

Question. What is the current state of the research on effective strategies to discourage youth from smoking and chewing tobacco?

Answer. Most people who start smoking are younger than age 18. Several studies have shown that school-based tobacco prevention programs can significantly reduce or delay adolescent smoking. Tested science-based programs have produced differences in smoking prevalence between intervention and nonintervention groups ranging from 25 percent to 60 percent and persisting for 1 to 5 years after completion of the programs. They are more effective if supplemented by booster sessions and community wide programs involving parents and community organizations and including school policies, mass media, and restrictions on youth access. Tobacco use prevention education needs to start in elementary school and continue through middle and high school grades.

Numerous published studies have shown that the combination of enforcing laws that restrict tobacco sales to minors and educating merchants can reduce illegal sales of tobacco to minors. A graduated system of civil penalties on the retailer, including temporary revocation of tobacco licenses in areas where tobacco retail licenses are required, has been shown to be an effective enforcement strategy. It is critical that access restrictions be combined with a comprehensive program that reduces the availability of tobacco from friends who are not minors and limits the appeal of tobacco products.

Tobacco advertising and promotion activities appear both to stimulate adult consumption and to increase the risk of youth initiation. Children buy the most heavily advertised brands and are three times more affected by advertising than are adults. One study estimated that 34 percent of all youth experimentation with smoking in California between 1993 and 1996 can be attributed to tobacco promotional activities.

Finally, programs that successfully assist young and adult smokers in quitting can produce a quick and significant public health benefit.

ORGAN TRANSPLANTATION AND ALLOCATION ISSUES

Question. Explain the actions taken by HHS so far to respond to the requirement in the omnibus appropriation to work with the IOM and the GAO to report on organ allocation policies of the OPTN. Describe working relationships HHS has with IOM and GAO.

Answer. Based on the Omnibus Consolidated and Emergency Supplemental Act of 1999, and at the request of the IOM and the GAO, Departmental staff have met with the principals at the IOM and GAO to discuss the study. While the Department has not been requested by the IOM to be directly and substantively involved in the study to date, we are available to them to provide data and other forms of assistance as needed and have recently provided the IOM with reference documents cited in the OPTN regulation. The Department also testified at the IOM's initial Steering Committee (along with the GAO and others in the transplant community) and agreed to provide whatever data and analyses the IOM needs to complete its task.

Question. What is the status of the required report and its expected date of completion?

Answer. The IOM has announced that a series of three meetings will be held in March, April and May in Washington, DC and Irvine California to discuss various aspects of the study. It is projected that the study will take six months to complete and we anticipate the IOM report to be completed by September.

Question. In the pending regulations for the OPTN issued on April 2, 1998, HHS adopted the following performance goals for organ allocation: standardized listing criteria, standardized criteria for determining medical status, and policies that give priority to those whose needs are most urgent, taking into account differences in waiting times and similarities in medical status. Explain current Federal organ allocation policies (including the liver allocation guidelines), and how the HHS's performance goals are assessed relative to those policies.

Answer. The current organ-specific allocation policies are voluntary. They are developed and implemented by the United Network for Organ Sharing, the federal contractor for the Organ Procurement and Transplantation Network (OPTN). However, these policies are not implemented uniformly nationwide. The OPTN permits organ transplant programs, states, or regions, to agree to alternate methods for sharing donated organs. For examples, see attached "variances."

Current OPTN organ allocation policies generally allocate organs in a geographically tiered system under which organs are offered to suitable transplant patients within a local geographic areas, and if no suitable match can be found, then to transplant patients outside the local area within an OPTN region (with one exception, New York State, the regions are multi-state) then finally to other patients nationwide. Patients are ranked within each of these geographic areas based on a number of criteria, including medical urgency. The time patients have waited for a transplant generally is used as a tie breaker if more than one suitable candidate is waiting. The "local" area is typically the service area of the transplant program's organ procurement organization, although as noted above, broader sharing is permitted under variances that have been approved by the OPTN. In addition, for certain donated kidneys that are good medical matches for waiting patients, national sharing is required.

The OPTN has adopted standardized minimum listing criteria and medical urgency (status) definitions for liver allocation, and for liver and heart allocation give substantial weight to medical urgency.

The HHS performance goals build on the OPTN's practices and are intended to better fulfill the National Organ Transplant Act. They require the transplant community to rely more on medical criteria for organ allocation (as directed by the statute) and eliminate the reliance on non-medical geographic boundaries. The first two performance goals (standardized minimum listing criteria and uniformly defined status categories) build on the approach the OPTN has taken already for liver allocation. The third regulatory criterion—reducing disparities in waiting times among similarly situated transplant candidates, consistent with sound medical judgment—is consistent with the statute which directs that the allocation system treat patients equitably.

The HHS performance goals are not, however, specific allocation policies which can be compared to current OPTN policies. Rather, these goals are to be implemented by allocation policies developed by the transplant community and, therefore, comparison of OPTN- developed policies with the allocation policies to be developed under the regulations cannot be made at this time.

Question. What are the short- and long-term economic and social costs associated with current organ allocation policy?

Answer. There are substantial short- and long-term economic costs associated with the current allocation system.

As discussed in the preamble to the Department's regulation, the transplant industry may account for $3.5 billion in estimated billed charges. There are several measures that each partially describe the costs of the current system: wide geographic disparities in waiting times; deaths; reduced quality of life; and, life years unnecessarily lost.

The recent 1997 Report of the OPTN: Waiting List Activity and Donor Procurement illustrates how waiting times vary, even in adjacent geographic areas. For patients with blood type O (the most common blood type) the median waiting time was 511 days in New York City, while the median waiting time in bordering northern New Jersey was 56 days. In Iowa, which had the shortest waiting times among the 66 OPO areas, the wait was 46 days, compared with neighboring Nebraska at 596 days. There may be other contributing causes, such as more aggressive listing, which could account for some of this variation; however, much of it is caused by the current allocation system, which emphasizes arbitrary geographic boundaries as a

basis for organ allocation. Patients trying to select a transplant program under the current system are forced to decide how to factor these longer waits, an concomitant increased risk of death while waiting into choices about which program to select.

Another indication of the costs of the current system are the deaths of patients awaiting transplants. Under the current system, deaths for patients awaiting transplants have increased from 1,502 in 1988 to 4,065 in 1996. OPTN modeling of alternative liver allocation policies suggests that some of these deaths are unnecessary.

For patients awaiting kidney transplants, (over two-thirds of the waiting list and over one-half of the annual transplants), the costs are both unnecessary deaths which occur while waiting (about 1,800 in 1996) and a diminished quality of life while on dialysis.

A cost which represents yet another measure of the costs of the current system is the avoidable years of life lost. It is difficult to quantify the magnitude of these costs, as compared to those life years unavoidably lost due to the general shortage of donated organs or other factors. This difficulty stems from the fact that neither the OPTN nor others have developed models to demonstrate the magnitude of this cost on organs other than livers. The liver modeling results, however, are instructive. Both the OPTN model and a model which uses somewhat different assumptions suggest that alternatives to the OPTN-developed liver allocation system that reduce the reliance on the current artificial "local" geographic boundaries, even alternatives that do not fully address the regulation's three performance goals, would "save" life years. In addition, the alternatives modeled reduced deaths overall.

Question. In December 1996, 3 days of departmental hearings on organ transplantation were held. In December 1997, the Clinton Administration launched the National Organ and Tissue Donation Initiative whose goal is to increase the national supply of organs by 20 percent in 2 years. What has the Department done to pursue the realization of that goal.

Answer. In the 14 months since the launch of this multi-faceted and multi-year Initiative, several of the Initiative's proposed projects that show promise of increasing donation have been implemented or initiated. As an example, the Initiative called for a Federal rule requiring hospitals to refer all deaths to organ procurement organizations (OPOs). In response, HCFA issued a final rule, effective August 21, 1998, for Conditions for Hospital Participation in Medicare and Medicaid Programs that requires referral of all deaths and imminent deaths to the OPO and adequate training for hospital-based staff who request donation. Modeled after Pennsylvania's successful required referral law, we anticipate that this rule, in conjunction with other Initiative efforts, will yield a 20 percent increase in donation by August 2000. In support of this rule, HCFA and HRSA are jointly planning conferences to develop guidelines for training hospital-based requesters. These conferences will also review best practices for hospital and OPO collaboration and their interaction with potential donor families.

In 1998, the Department sponsored a 2-day conference to identify best practices for evaluating strategies to increase donation. This conference led to the identification of a number of important approaches which need to be further explored. As a result of the increase in the 1999 HRSA Appropriation, a new extramural grant program is currently being developed which will focus on methods to increase donation. In addition, the Department hopes to serve as a model for all government agencies and employers by encouraging HHS employees to consider donation. Donation information materials have been provided to approximately 100 federal government agencies for distribution, and pay stubs have included donation messages.

The Initiative also provides electronic information to the public through its own web site (www.organdonor.gov), as well as a web site developed in partnership with the National Kidney Foundation (www.kidney.org) to provide information to donor families and the general public, and another through the University of Michigan (www.transweb.org/journey) to educate school-age children about donation and transplantation.

Question. Discuss any partnership agreements achieved or planned between the HHS and nongovernmental organizations to increase organ and tissue donation.

Answer. HHS is developing a broad national partnership of public, private, and volunteer organizations to assist in the implementation of the Initiative. A Partnership Kit has been developed with resources to aid in educational activities. The following examples show the variety of organizations and activities in several arenas supporting the National Organ and Tissue Donation Initiative:

In the health care community, the American Medical Association and the American Academy of Family Physicians are partnering with HHS to encourage physicians to make donation materials available in their offices and to discuss donation with their patients.

The legal field is involved through a partnership between the American Bar Association and HHS in which attorneys are encouraged to discuss donation with their clients during estate planning.

In the educational setting, the American College Health Association, a national organization with 900 member institutions, has been funded by HRSA in a demonstration project that will implement and test the effectiveness of college campus campaigns to increase donation.

The faith community has supported a number of efforts, including a partnership between the Congress of National Black Churches, representing 65,000 congregations with an excess of 20 million parishioners, and HHS in a national project to educate its members about organ, tissue, and bone marrow donation.

Businesses also are involved in partnerships, such as The Home Depot's program to conduct organ and tissue donation education activities for employees.

In one of several efforts to focus on minority issues, the National Minority Organ and Tissue Transplant Education Program is designed to empower minority communities to become involved in education activities to increase the number of minority donors.

Donor and recipient groups are involved in awareness and appreciation programs, such as the National Donor Recognition Ceremony and Workshop conducted in collaboration with the National Kidney Foundation's National Donor Family Council.

National Donor Day—Saturday February 13, 1999. The "celebration of life" volunteers from the transplant community prepared a one-day blitz to promote donor awareness. HHS, along with the Saturn Corporation and the United Auto Workers and other nationwide groups, partnered in this event. Volunteers visited participating Saturn Corporation automobile dealers and learned how donating "Five Points of Life"—whole blood, platelets, umbilical cord blood, bone marrow, and organ and tissue donation, can extend life to others.

SLOW SPENDING OF TANF FUNDS

Background

The 1996 welfare reform law replaced the Aid to Families with Dependent children (AFDC) program with TANF. The TANF program provides fixed block grants to the states. The basic TANF block grant is $16.5 billion annually for fiscal year 1997 through fiscal year 2002. TANF also includes supplemental and bonus funds. TANF grants remain available for use by the states without fiscal year limitation. Though TANF grant awards are made quarterly, actual cash (outlays) is not transferred to the states until they make expenditures in their TANF programs. As of September 30, 1998, TANF balances (grants that have not been outlaid to the states) totaled $7.1 billion. Some of this balance reflects funds obligated but not yet expended by the states. The Department of Health and Human Services (DHHS) estimates that obligated and unexpended TANF funds totaled between $3 billion and $3.5 billion at the close of fiscal year 1998.

The President's fiscal year 2000 budget proposes some savings from freezing a special supplemental grant targeted to states with high population growth and low historical welfare spending per poor person. An estimated 17 states qualify for this supplemental grant; most of these states are in the South or West.

Question. What accounts for the slow spending of TANF funds?

Answer. We have received a great deal of information from States regarding the reasons for the delays in their TANF spending.

First, caseloads have dropped sharply, and many States did not expect or budget for such a decrease. State legislators generally appropriated fiscal year 1998 TANF funds in the first half of calendar year 1998. Since then, unexpectedly sharp caseload declines gave States additional funds to serve needy families. However, it takes time to develop and implement new spending initiatives. Many States required legislative action to reprogram large amounts of funds from one activity, such as cash assistance, to another such as post-employment supportive services. Fiscal year 1999 legislatures are now in session, and States are now appropriating the additional funds resulting from such unexpectedly large caseload declines.

Second, many States are still continuing to change the focus of their TANF programs from income support to work support. State are finding that many of families remaining on the rolls face severe barriers to employment, such as low levels of education and skills, substance abuse, mental health problems, and disability. These barriers can require major investments to overcome. As many TANF families begin to hit time limits, it will become critical for States to make additional investments with their TANF funds in order to get these families into the workforce and stay employed.

According to the latest data, 17 States obligated all their fiscal year 1997 and fiscal year 1998 TANF funds: Alaska, Arkansas, California, Connecticut, Delaware, Illinois, Indiana, Maine, Massachusetts, Mississippi, Missouri, Montana, Ohio, Oregon, Texas, Virginia and Wyoming. We expect to see States obligating and spending more of their TANF funds in fiscal year 1999, as State appropriations decisions made this year move toward spending more on work activities and the intensive services necessary to help recipients find jobs and succeed in the workforce.

Question. Have states increased or decreased their spending per family under TANF compared with AFDC? By how much?

Answer. AFDC and TANF spending per family measures are not directly comparable, since States have much more flexibility under TANF to invest in services that families need to move from welfare to work and to provide supports for working families. States are offering a wider array of services under TANF than was allowable under the former AFDC, JOBS and the Emergency Assistance programs. In addition, States are not required to report on the number of families receiving services that are not defined as "assistance," such as one-time only assistance. Therefore, any figure showing TANF spending per case will not reflect all families being served by States under TANF.

However, it is possible to compare spending on cash assistance between the two programs. In fiscal year 1996, the last full year of the AFDC program, the total average monthly benefit per case was $374. In fiscal year 1998, the total average monthly spending per case on "cash and work-based assistance" was $383, a two-and-a-half percent increase.

Question. The President's budget projects increases in TANF outlays in fiscal year 2000. Do these projections indicate expected caseload increases, or do you expect spending per TANF family to increase?

Answer. We expect TANF outlays to increase in fiscal year 2000 due to increases in State spending on TANF families. As TANF caseloads have declined, State are finding that many of families remaining on the rolls face severe barriers to employment, such as low levels of education and skills, substance abuse, mental health problems, and disability. These barriers can require major investments to overcome. These investments will require greater than average TANF funding per recipient.

In addition, some States have not had time to enact legislation to shift the focus of their TANF programs from cash assistance to work support. We expect a substantial increase in TANF spending as State appropriations decisions made last year translate into additional expenditures for new services.

Question. The budget documents show a balance of $7 billion in unexpended TANF grants at the end of FY1998. The DHHS has been reporting a different balance of between $3.0 billion and $3.5 billion. Could you explain the difference between the budget numbers and the DHHS figures?

Answer. The $3 billion figure represents the cumulative unobligated balance (from both fiscal year 1997 and fiscal year 1998 TANF funds) as reported by States as of September 30, 1998. The unobligated balance represents the amount of TANF grants that States have not yet obligated (that is, entered into contracts or made other binding spending plans). The $7 billion figure is the cumulative TANF cash balance remaining in the Treasury as of September 30, 1998. This balance represents funds that have not been drawn down (or, "outlaid") by States and includes funds that States have already committed to spend.

Question. DHHS reports that states have obligated, but have yet to expend some funds. What types of activities are these obligations for? Do subgrants to counties or other localities count as state obligations in the TANF program?

Answer. Obligations refer to amounts States have committed to spend, but have not yet spent. According to our financial regulations, obligations represent the amount of orders placed, contracts and subgrants awarded, and similar transactions that will require payment by the State during some future period. An example of this may include funds a State has committed to pay under a contract for computer systems, but which the State has not yet paid. Subgrants to counties or other localities may count as State obligations in the TANF program.

Question. How much of the fiscal year 1998 balance reflects state "rainy day" funds? Are these funds adequate, inadequate, or more than adequate to meet the extra costs of a recession should it start this year?

Answer. States are not required to report information on their "rainy day" funds, so we do not know how much of the unobligated balance has been dedicated by States for that purpose. As part of the welfare reform legislation, Congress gave States the authority to save unspent TANF funds for future contingencies. In the event of a recession, States will have these TANF funds available, along with funds from the Contingency Fund. As part of the fiscal year 2000 Budget, we are pro-

posing to uncap the Contingency Fund to make it more responsive to State needs during an unforeseen recession.

Question. What is the Administration's rationale for proposing to freeze the supplemental grant targeted to states with high population growth and low historical expenditures per poor person?

Answer. The TANF Supplemental Grants were intended to provide additional funds to States with high population growth and/or low per capita welfare spending that might be burdened by a fixed TANF block grant. However, since the enactment of welfare reform, the 17 States receiving these Supplemental Grants have on average experienced the same, or even greater, caseload declines as other States. Therefore, the Administration proposes to freeze these Supplemental Grants for fiscal year 2000 at their fiscal year 1999 levels. The 17 States will still receive Supplemental Grants totaling $159.7 million in fiscal year 2000, but won't receive the automatic 2.5 percent increase authorized by PRWORA.

Background

The President's fiscal year 2000 budget proposes a series of welfare-to-work initiatives, including a $1 billion extension of the Department of Labor's welfare-to-work grant program, welfare-to-work housing vouchers, and job access grants. It also proposes a major child care initiative to increase funding for the Child Care and Development Fund (CCDF) by $7.5 billion over the next 5 years. Under TANF, states also have the flexibility to use block grant funds for welfare-to-work and child care activities.

Question. Given the amount of unspent TANF money available, are these additional dollars necessary?

Answer. States need to invest both TANF and Welfare to Work (WtW) resources to ensure that all welfare recipients, including those with the greatest barriers to employment, can move to self-sufficiency within the time limits.

The President's Budget requests $1 billion to continue the work begun under the current Welfare to Work program, which is administered by the Department of Labor and provides funds to State and local areas that help the hardest-to-employ welfare recipients and non-custodial parents get and keep their jobs.

The proposed reauthorization of the Welfare to Work program has two main objectives:

To continue to provide transitional assistance to hard-to-employ current and former welfare recipients living in high-poverty areas; and, To strengthen families by helping noncustodial parents increase their employment and earnings so they can better support their families.

The unspent TANF money available is simply inadequate to meet these goals. (It is important to note that 17 States have obligated all their TANF funds for fiscal year 1997 and fiscal year 1998, and these States do not have "unused" TANF funds left to spend on child care and Welfare-to-Work services.) States are finding that many of the families remaining on the rolls face barriers to employment such as limited education and skills, substance abuse or mental health problems, or a disability. These barriers can require major investments to overcome—investments greater than the average TANF funding per recipient. WtW is the only program with funds dedicated to the hardest to serve welfare recipients. Furthermore, WtW funds can be spent on those who have exhausted their TANF time limit but are still in need of employment services.

Question. Are there any work activities funded under the Department of Labor's welfare-to-work grant program that cannot be funded under TANF using already available funds?

Answer. States need to invest both TANF and WtW resources to ensure that families with the most intensive service needs (such as those with low skill levels, substance abuse problems, and disabilities) can move to self-sufficiency. The WtW grant program has a more specific purpose than TANF, with funds are directly targeted to help harder-to-serve TANF recipients and non-custodial parents. As caseloads decline, States are finding that many of the families remaining on the rolls face barriers to employment such as limited education and skills, substance abuse or mental health problems, or a disability. These barriers can require major investments to overcome—investments greater than the average TANF funding per recipient. WtW is the only program with funds dedicated to the hardest to serve welfare recipients. Furthermore, WtW funds can be spent on those who have exhausted their TANF time limit but are still in need of employment services. Therefore, additional WtW funds will ensure that the hardest-to-employ welfare recipients living in the highest poverty areas will get the help they need to secure work and succeed in the work place.

If States use WtW funds to help these very important groups of individuals, they need not amend their State TANF plans or possibly redefine their State statute. Whereas, to fully help non-custodial parents using TANF funds may well involve defining this parent as a member of an eligible TANF family. This could easily mean a need to alter State law and amend the TANF plan.

Furthermore, some States wish to reserve a share of their Federal TANF funds for a rainy day; they want to know they have additional funds available should they experience a population increase or a regional recession.

As we continue to move persons off the rolls, it is essential that all of these funds be available to meet the most intense needs of the harder-to-serve population.

Question. Can states fund the activities of the proposed welfare-to-work housing voucher and job access grant programs with TANF funds?

Answer. TANF funds may be used in a wide variety of ways that are consistent with the goals of the TANF program. The uses may include providing housing assistance and other supportive services that help families attain and maintain employment. Examples of such supportive services include, but are not limited to, transportation, child care, job readiness assistance, case management, job training and re-training activities, job retention services, and post-employment follow-up services.

The Department of Housing and Urban Development welfare-to-work rental voucher initiative supports our welfare-to-work efforts by providing rental subsidies to families. These subsidies follow the family and enable them to move to decent housing that is closer to employment and training opportunities or service sites such as day care facilities without requiring the family to incur excessive rental costs. Thus, this program will further help TANF-eligible families transition from welfare to work.

Similarly, the Department of Transportation has also contributed to the welfare reform efforts through its Job Access program. This program assists States and localities in developing flexible transportation services that connect welfare recipients and other low income persons to jobs and other employment related services. States may use Federal TANF funds to meet the cost-sharing requirement of the Jobs Access program.

Question. Can states spend the currently unused TANF money on child care?

Answer. As of September 30, 1998, 17 States had obligated all their fiscal year 1997 and fiscal year 1998 TANF funds, and therefore do not have any "unused" funds to spend on child care. The remaining States may spend their unobligated balances on child care, but may be reluctant to do so for several reasons. While caseloads have dropped dramatically nationwide, States face critical challenges as they attempt to help the remaining welfare families move into the workforce and gain self-sufficiency. This next stage of welfare reform may prove costly, and States may be reluctant to use their TANF funds on child care when they anticipate new spending on the increasing share of their caseload with major barriers to employment such as illiteracy, substance abuse and mental health issues. Also, some States may choose to use their unobligated balances as "rainy day" reserves to cover the increased costs of an unforeseen economic downturn.

Our child care initiative is designed to provide assistance low income working families—not necessarily welfare families. This proposal prevents welfare from being the only way for low-income families to gain access to child care. In far too many parts of the country, the only child care available is for welfare families making the transition to work. Low- income families, many of whom never have been on welfare, pay on average 25 percent of their incomes on child care.

Our requested increase of $7.5 billion over 5 years for the Child Care and Development Fund will dramatically increase the availability and affordability of child care for low income working parents. These funds, together with the existing child care funds, will enable States to provide assistance for an additional one million children by 2004, for a total of 2.4 million children. We are also requesting $3 billion for the Early Learning Fund, which will provide challenge grants to States and communities to promote school readiness, and improve early learning and the quality and safety of child care.

USES OF TANF BLOCK GRANTS

Background

A state is permitted to use Federal TANF funds for all activities it was allowed to conduct under welfare programs operated under pre-TANF law: cash benefits, emergency aid, child care, and work and training activities. Additionally, states may use TANF funds for activities "reasonably calculated" to accomplish the purposes of

the program.[3] Though the activities permitted under TANF are relatively broad, providing Federal TANF "assistance" to a family triggers the application of certain program requirements to that family: work requirements, child support requirements, reporting requirements, and time limits. The DHHS issued proposed regulations on November 20, 1997 detailing rules for the expenditure of funds and application of TANF requirements. Final regulations have yet to be published.

Question. In proposed regulations, DHHS sets the rules for expenditure of funds, including defining when TANF requirements apply and what constitutes a family receiving TANF "assistance." When will these regulations be finalized?

Answer. We expect the regulations to be published this spring.

Question. Do you think that the absence of final regulations about the uses of TANF funds has slowed state program innovations and contributed to the slow spending of TANF funds?

Answer. While some States may be hesitant to undertake new spending initiatives in the absence of final rules, we have advised them that they may operate their TANF programs in accordance with a reasonable interpretation of the statute until we issue the final rules. Thus, States could undertake new initiatives that were consistent with a reasonable interpretation of the statute without fear of incurring penalties. We have also used every available occasion (such as conferences and meetings with States, intergovernmental groups, and advocates) to inform States and other interested parties there are clear opportunities to use TANF funds in a variety of innovative ways to help all families attain and maintain self-sufficiency. Finally, we have emphasized the importance of helping harder-to-serve family members overcome employment obstacles, so that all clients have the chance to succeed.

Background

TANF permits limited transfers (up to 30 percent of the grant) to the Child Care and Development Fund (CCDF) and Social Services Block Grant (SSBG). For fiscal year 1997 through fiscal year 2000, transfers to S SBG are ftuther limited to 10 percent of the TANF block grant. For fiscal year 2001 and later years, transfers to SSBG are limited to 4.25 percent of the TANF block grant. The President's budget proposes to accelerate to fiscal year 2000 the scheduled reduction in the share of TANF funds that may be transferred to SSBG.

Through June 30, 1998, states have transferred only 3 percent of their fiscal year 1998 TANF grant to CCDF. Through June 30, l998, states transferred 5 percent of their fiscal year 1998 TANF grant to SSBG.

Question. Why do you think states are using only a small part of their authority to transfer funds from TANF to the CCDF?

Answer. Twenty-eight States took advantage of the option to transfer TANF funds to child care in fiscal year 1998, transferring some $740 million. The amount of TANF funds transferred to child care tripled between fiscal year 1997 and fiscal year 1998. In addition, some States may be reluctant to transfer their TANF funds to child care when they anticipate new spending on the portion of their welfare caseload with major barriers to employment. States may also save some portion of their TANF funds as "rainy day" reserves to cover the costs associated with an unforeseen economic downturn.

Question. What types of requirements apply to transfers to the Child Care and Development Fund. Is there a deadline for the obligation and expenditure of these funds?

Answer. Funds transferred from TANF to the Child Care and Development Fund (CCDF) are subject to the requirements applicable to the Discretionary Fund of the CCDF. As indicated in the CCDF Final Rule (45 CFR 98.60), States must obligate their Discretionary Funds either in the year they are received (or transferred from TANF) or in the succeeding fiscal year. They must liquidate (expend) their funds by the end of the third fiscal year. Thus, if a State transfers funds to child care in fiscal year 1999, it must obligate these funds by the end of fiscal year 2000 and must expend these funds by the end of fiscal year 2001.

Question. What is the Administration's rationale for proposing to accelerate (to fiscal year 2000) the scheduled reduction in the share of TANF funds that may be transferred to SSBG?

Answer. As you may recall, Congress included a provision in the Transportation Equity Act of the 21st Century (Public Law 105–178) to reduce the percentage of TANF funds that States may transfer to Title XX from 10 percent to 4.25 percent,

[3] The stated purposes are to provide assistance so that children may be cared for in their own homes; end dependence of needy parents on government benefits by promoting job preparation, work, and marriage; prevent and reduce the incidence of out-of-wedlock births; and encourage the formation and maintenance of two-parent families.

beginning in fiscal year 2001. In light of the $471 million increase that we are proposing for the Title XX SSBG program for fiscal year 2000, our budget recommends that Congress take action to make the transfer cap reduction to 4.25 percent effective in fiscal year 2000. This approach will allow States to spend their TANF funds for the investments critical to help welfare families move into the workforce and gain self-sufficiency, while providing the States with additional funds for other social services and populations.

Question. Approximately how many persons or families have been served by TANF transfers to SSBG? What types of services have states funded using TANF transfers to SSBG?

Answer. States are not required to report how many persons they are serving specifically with TANF transfers to SSBG. States may use funds transferred from TANF to SSBG for the same type of services funded with their annual SSBG allotment. Data show that most States use SSBG to support child care (47 States), child protective services (46 States), home-based services (45 States), and case management (38 States). States reported spending 22 percent of funds on child welfare (foster care, adoption and protection services), 15 percent on child care, 10 percent on home-based services, and 7 percent on prevention and intervention services.

CONTINGENCY FUND

TANF includes a "contingency fund," which would provide matching grants to states that meet certain criteria. There are both state and national caps for the contingency fund. A state's contingency funds are limited in each year to 20 percent of its TANF block grant, and nationally contingency funds cannot be more than $1.96 billion. To qualify for contingency funds a state must have high and increasing unemployment or food stamp caseloads 10 percent higher than in fiscal year 1995. It must also meet a maintenance of effort requirement stricter than the overall TANF maintenance of effort requirement. To date, one state received contingency funds. The President's fiscal year 2000 budget proposes to rescind the TANF contingency fund and replace it with a new, uncapped contingency fund that is not described.

Question. What analysis has the Administration done to show that the current contingency fund would be inadequate to meet the needs of the states during a recession? What provisions of the contingency fund would bar needy states from receiving sufficient Federal funds: the unemployment or food stamp caseload qualifying criteria, the spending requirements, or the caps on state and national contingency funds?

Answer. We have not had the opportunity to examine the adequacy of the Contingency Fund during a recession. The Administration's budget estimates assume that favorable economic conditions will continue. Furthermore, it would be difficult to develop an accurate analysis of the demand on the Contingency Fund under a recession. It would be insufficient to estimate the number of States that would meet the Fund's trigger requirements, as other uncertain variables include the number of States meeting the Contingency Fund maintenance of effort (MOE) requirements and the amount of expenditures that exceed the MOE level.

Some members of Congress, States, and advocacy groups and have criticized the Fund's cap, saying that the $1.96 billion would be insufficient in the event of an unforeseen economic downturn. As stated in last year's Report on the Status of the Contingency Fund, the Administration noted that funding of the Contingency Fund would likely be insufficient during a severe recession.

Question. The budget does not specify the details of the Administration's contingency fund policy. Aside from uncapping it, what changes to the contingency fund do you propose to make?

Answer. The Administration is currently developing a legislative proposal that will make the Contingency Fund more responsive to State needs in the event of an unforeseen economic downturn. We will transmit it to Congress as soon as it is finalized.

Question. Has the Administration done any analysis to show what the effects of its policies would be under varying economic circumstances? For example, how much would the proposal cost if there were a recession comparable to the 1990–91 recession?

Answer. It is not possible to develop an accurate estimate of the need for Contingency Funds under a recession like that of the early 1990s. Due to the changes made to the Food Stamps program by welfare reform, comparable Food Stamps caseload data for that time period is not available to assess the number of States that would have meet the Food Stamp trigger.

However, in last year's Report on the Status of the Contingency Fund, we provided some context by looking at the number of States that would have met the unemployment rate trigger during the early 1990's and the number of months they would have done so. During the period 1991 though 1994, 39 States would have met the unemployment trigger for at least one month, and would have been eligible to receive provisional payments from the Contingency Fund in 34 percent of the months during that time period. To assess the adequacy of the Contingency Fund, one would need to know how many States would meet the Contingency Fund MOE requirements and the amount of expenditures exceeding the MOE level.

ADMINISTRATIVE COST ALLOCATION

Background

Before the 1996 welfare law, states often charged "common" administrative costs for administering cash welfare, Food Stamps, and Medicaid to the Aid to Families with Dependent Children (AFDC) program. When AFDC was replaced by the TANF block grant, all costs charged to AFDC—including common administrative costs for administering AFDC, Food Stamps, and Medicaid—were folded into the TANF block grant. The Agricultural Research Act of 1998 prospectively reduces the Federal reimbursement for food stamp administrative costs by the food stamp "share" of common administrative costs included in the TANF block grant. The President's fiscal year 2000 budget proposes to make similar reductions in the Federal reimbursement for Medicaid administrative costs. Additionally, the Administration now requires states to split the common costs for administering TANF and other public assistance programs with all "benefitting programs," including food stamps and Medicaid.

Question. How much will fiscal year 2000 Food Stamp and Medicaid spending be increased because of the Administration's requirement that common costs be split among TANF, food stamps, and Medicaid?

Answer. With the repeal of the AFDC program and the enactment of TANF, states began to amend their public assistance cost allocation plans to charge activities to programs in the proportion to which the programs benefitted from those activities. This change in the way states began to allocate costs was consistent with OMB circular A–87 and generally accepted accounting principles, although it differed with general practice under the AFDC program, where legislative history called for common costs to be assigned to AFDC. Our projections, which are based on determinations pursuant to Section 16(k) of the Food Stamp Act, include the following increases as a result of the way states are allocating common costs:

	1999	2000	2001	2002	2003	2004
Food Stamps	$226	$230	$235	$240	$250	$255
Medicaid	295	305	325	345	375	405

With the fiscal year 1999 President's Budget, the administration required states—including those that had not already submitted revised cost allocation plans—to move to this cost allocation approach for TANF, Food Stamps and Medicaid, and at the same time, it proposed reducing Medicaid and Food Stamp administrative costs to recapture these costs that were included in the TANF block grant. The Food Stamp administrative expenditures were reduced as part of the Agriculture Research, Extension, and Education Reform Act of 1998. In the fiscal year 2000 budget, the administration again proposes to reduce Medicaid administrative costs, which are increasing as states allocate costs among all three programs. This proposal is projected to save $1.2 billion over five years, net of increased TANF spending.

Question. Do any programs other than Food Stamps and Medicaid have to pick up administrative costs formerly charged to AFDC/TANF?

Answer. All Federal programs are expected to allocate and charge administrative costs based on their relative benefit unless there are statutorily-based exceptions. The only major program that States should have been charging some administrative costs to AFDC is the Child Support Enforcement program. Current ACF regulations prevent these administrative costs from being paid for by the Child Support Enforcement program—which has an enhanced Federal matching rate. The amount and extent of these potential charges is not easily known, but they would be relatively small in comparison to the Medicaid and Food Stamps cost allocation determinations made under the Agriculture Research, Extension and Education Reform Act.

Question. The Administration's proposal cuts Medicaid spending based on pre-1996 common administrative costs, when AFDC eligibility conferred automatic Med-

icaid eligibility. The 1996 welfare law delinked cash welfare and Medicaid eligibility. How many states still determine cash welfare (TANF) eligibility in a different office from where Medicaid eligibility is determined?

Answer. Very few states still determine TANF eligibility in a different office from where Medicaid eligibility is determined. Specifically, five States' staffs are not co-located and six States comprise both joint and separate staffing (depending on the county in some States).

HEAD START

Question. Head Start has received large increases in funding in recent years. What assurances can you give the Committee that these new funds can be used effectively without sacrificing the quality of Head Start?

Answer. In the last several years Head Start has made a significant investment in improving quality in Head Start. We have made available significant funding increases to programs to allow them to address quality issues, particularly issues related to improving the quality and number of staff employed by Head Start programs. Salaries have been increased, training opportunities have been expanded and new, needed, staff have been hired. At the same time we have been investing in quality we have been clear to programs that they must use these resources well and deliver services of consistently high quality. Where programs have failed to do this, we have advised them of the need to improve and have made available support resources to help them. Programs that could not or would not improve were terminated and, in fact, since 1993 more than Head Start 100 programs have either been terminated or have relinquished their grant.

In fiscal year 2000, we will continue this "carrot and stick" approach. Last year's Head Start reauthorization increased the allocation of new funds dedicated to quality. Based on this formula, the President's budget request, if appropriated, would provide for almost $257 million in quality improvement funds. These funds will allow programs to continue to invest in program improvement by improving staff salaries to attract and retain quality staff, by adding additional staff in such important areas as family workers and by improving staff training. We will continue the efforts we began in fiscal year 1999 to focus a portion of these new funds on increasing the number of Head Start teachers with degrees in early childhood education, or related fields, as required by the recently reauthorized Head Start Act. We will also continue to insist that programs provide high quality services or we will move to discontinue their grant. This Administration is fully committed to Head Start quality and the President's proposed fiscal year 2000 budget will continue previous efforts to assure that every enrolled child and family in Head Start receives services of consistently high quality.

Question. The President has stated a goal of serving 1 million children in Head Start by 2002. Was the budget request derived by calculating the amount needed to reach that goal, irrespective of any needs assessment? What is the motivation behind such a large funding increase, given the fact that the program has already grown so substantially?

Answer. The President has long been committed to serving 1 million children in Head Start. According to the most recent census data, there are almost 1.8 million poor children in this country who are either three or four years old, as well as 2.6 million poor children under the age of three. The President's commitment to serving 1 million children will meet just a small percentage of this need.

The fiscal year 2000 budget proposal was made in a time of tight budget constraints and the need to make difficult decisions about which programs should be considered as priorities, proposed for funding increases, and which programs should not. The President's fiscal year 2000 increase, if appropriated, would represent the largest single year increase for Head Start and is intended to enhance program quality and continue the path started several years ago of increasing enrollment to reach, eventually, 1 million children. Although Head Start has seen significant growth in the last several years, this Administration believes this increase is important to both allow Head Start programs to reach out to additional, unserved children and families as well as to allow programs to better meet the needs of currently enrolled families, many of whom are being significantly impacted by welfare reform and the need to find quality child care for their children. While much has been done in the last several years, there continues to be much that needs to be done to give as many of America's disadvantaged children as possible a true "Head Start."

ADMINISTRATION ON AGING

Question. The President is requesting $125 million for a new "National Family Caregiver Support Program." Could you explain the goals of this program and how the funds will be spent? Will you take steps to gain authorization for this program?

Answer. The fiscal year 2000 budget includes a new $125 million National Family Caregiver Support Program which will provide essential assistance to approximately 250,000 families caring for an older relative. Legislation to authorize this Program was submitted to Congress on January 15th, 1999. The National Family Caregivers Support Program consists of five components.

—Individualized information on available resources to support caregivers;
—Assistance with locating services from a variety of private and voluntary agencies;
—Caregiver training (e.g., the easiest and safest way to give someone a bath), support groups, and counseling to help caregivers cope better with the emotional & physical stresses of dealing with the disabling effects of a family member's condition;
—Respite care provided in the home, an adult day care center, or over a weekend in a nursing home or assisted living facility;
—Limited supplemental services to fill service gaps.
—Families, not social services agencies or government programs, provide most assistance to elderly persons who need help with everyday tasks, such as bathing, dressing, getting out of bed and toileting.
—The demands of providing this care can be very emotionally and physically draining. Studies show that half of all caregivers are themselves over 65, ⅓ are employed full time, and caregivers have higher rates of depression than non caregivers of the same age.
—Families need periodic help with these responsibilities in order to sustain themselves as caregivers. Studies have shown that respite care both relieves caregiver stress and can also delay nursing home entry for as long as a year.

Key Information

Of the funds for the National Family Caregiver Program:

—88 percent will be allocated by population-based formula grants to State agencies on aging which will allocate the fund to local area agencies on aging which collaborate with community service providers.
—10 percent of the program's funds will support innovation grants to enable the development and testing of program innovations to better address specialized caregiving issues, such as the development of emergency caregiving back-up systems, and to meet the needs of special populations, such as families in specific ethnic and minority communities or families in rural areas. 20 percent of these funds will be allocated to Indian Tribal projects.
—2 percent of the funds are dedicated to national activities of significance including program evaluation, training, technical assistance, research, and public education efforts to be conducted collaboratively by the AoA and other parts of HHS.
—This program is designed to be flexible to meet families' widely varying needs for services. The level of service provided to an individual family is based on an objective assessment of its needs.
—Services provided by the Family Caregiver Support Program are generally not provided by other Federal programs.
—*Medicaid*.—While Some States cover respite care under their Medicaid home and community based waiver programs, to qualify, the individual needing care must be assessed as needing nursing home care and have less than $2,000 in liquid assets. In addition, State waiver program ceilings often prevent even those who are eligible from receiving services.
—*Medicare*.—Medicare covers only limited personal care.

YEAR 2000 COMPLIANCE

Question. According to GAO, only 16 percent of state Medicaid systems were Y2K compliant? Does that fit with your assessment?

Answer. The GAO's report was done last summer and was based solely on self-reported information mailed to the GAO in response to a survey instrument that looked at the status of code renovation across a number of welfare-related programs including, but not limited to, Medicaid.

Since that time, HCFA has brought on an independent verification and validation (IV&V) contractor to perform on-site visits to every State to evaluate their Y2K progress.

A number of States have made significant progress since the GAO's report, but we remain concerned that others are still struggling to make their systems compliant. It is difficult for us to provide a percentage that are compliant because we will not have completed our site visits to all States until the end of April. After collecting this information, we believe it will take at least another month to analyze the results. We also plan to continue our site visits by visiting some of the States a second time, and, possibly, a third time between now and the end of the calendar year.

While the States are responsible for these systems, we believe we have a responsibility to not only track their progress but provide as much technical assistance as possible. For that reason, our contractor is making recommendations for corrective additions, re-allocation of resources, etc., where they believe States need to give additional attention and consideration. Of course, it is up to the States to use this information to the extent they believe appropriate since they know their systems and resources best.

I would like to point out that the GAO's survey only focused on one aspect of this problem—renovation of the code. While that is certainly a critical piece, HCFA's contractor is also concerned with the status of testing of the code once the changes have been made, the amount of outreach States are doing with regard to their data exchange partners including the provider communities, and the mission critical interfaces which State Medicaid systems depend upon to know who is eligible for the program and to make accurate and timely payments to providers. All of these were described in another GAO report on Y2K as being important, but their survey was not able to cover each of these topics in depth. From HCFA's perspective, however, only when these and other criteria are met, will we, based on our contractor's analysis, consider the State Medicaid programs to be fully Y2K compliant.

Question. What does HCFA plan to do to ensure that beneficiaries continue to receive medical services and providers are paid if some states' systems fail? .

Answer. HCFA has been encouraging State Medicaid Directors and Children's Health Insurance Program (CHIP) Directors to develop contingency plans in the event of the failure of State payment systems. HCFA plans to contract with a firm to review State contingency plans with an eye towards making suggestions to make the plans as strong as possible. HCFA believes that if any States are faced with systems which do not operate properly in January, 2000, such States would continue to pay providers on an estimated payment basis until the systems are restored to normal working conditions.

Question. Has HCFA developed a business contingency plan for sates that cannot meet the Y2K deadline?

Answer. While it is HCFA's position that States are responsible for developing their own business contingency plans, we realize that States need both policy guidance and technical assistance in developing the plans. HCFA has provided some general information about contingency planning to States, but have not yet placed any requirements on them. HCFA is now revising its plans on this and will be sending out information to States shortly which will require them to develop contingency plans, refer them to some additional general guidance on contingency planning that HCFA is using, and provide specific policy guidance for their use, including methods to enroll beneficiaries and pay providers if their regular systems fail. HCFA will also consider actions that HCFA or other Federal government agencies could take in the event of a State Medicaid system failure.

Question. Has HCFA given states any guidance to help them develop contingency plans?

Answer. Yes. HCFA has engaged the services of an independent verification and validation (IV&V) contractor which is visiting all 50 States plus the District of Columbia. The contractor is not only taking stock of the States' readiness for Y2K, but is also making suggestions to them concerning contingency planning. Furthermore, HCFA has provided information to States about where they can find helpful hints about contingency planning on the Internet and in other documentation. HCFA is now working on more specific direction and guidance for States, and will require States to develop and submit contingency plans. In addition, HCFA plans to contract for resources to review each contingency plan submitted, identify weaknesses, and provide assistance to States in strengthening their contingency plans.

Question. In your November 1998 Y2K quarterly report to OMB, HHS reported a Y2K cost of $942 million for HCFA and noted that this cost could increase by $350 million. That cost estimate went down in February 1999. Could you explain what accounts for this adjustment in funding requirements? Do you anticipate spending additional funds from the $2.25 billion in Y2K emergency funds for civilian agencies?

Answer. The scope and complexity of the Y2K project is constantly evolving as we learn more about the problem. We continue to update our budget estimates to re-

flect our latest thinking surrounding this issue. Changes in HCFA's budget estimates since the November 1998 quarterly report are primarily due to two factors: (1) the use of pessimistic assumptions and (2) inclusion of cost estimates for implementation of contingency plans.

We developed two sets of assumptions surrounding our Y2K funding needs: "most likely" and "pessimistic." In November, HCFA's budget estimates were based on the set of assumptions "most likely" to occur, but did indicate that these costs could increase significantly should some of our "pessimistic" assumptions occur. Since the development of these budget estimates we have accepted the self-certifications of almost 70 percent of external systems and all internal systems, so we felt that it was appropriate to remove the reference to our "pessimistic" assumptions in the latest budget estimates.

The budget estimates contained in the November 1998 quarterly report also included HCFA's initial attempt to estimate costs associated with the implementation of contingency plans. At that time, HCFA estimated that the agency could require approximately $311.2 million in contingency funding should problems occur necessitating implementation of contingency plans. The agency's recent quarterly report does not include costs of implementing contingency plans in its budget and spending estimates. HCFA will be developing the details of its contingency plans over the next few months and may include costs of implementation in future budget estimates.

At this time, we believe HCFA's latest budget estimates will support the Y2K funding needs of the agency. We will continue to update our budget estimates as the Y2K project evolves.

Question. Has HCFA developed a Medicare business contingency plan which can be implemented should system failures occur? How much does HCFA plan to spend in developing, implementing, and testing this plan? Has the plan been tested?

Answer. HCFA is following the GAO recommended model for contingency planning and is now in phase three (contingency planning). HCFA is now developing appropriate alternatives and selecting the best strategy for each critical process identified in its business impact analysis, and writing the contingency plans. HCFA expects to complete all phases of its contingency planning by June 30, 1999. Testing of each plan will occur once the plan is completely documented and all necessary decisions confirmed. HCFA will make needed modifications, based on testing, before June 30, 1999.

The current budget estimates include funding to support contingency planning for both external and internal systems. Because of the unknown factors surrounding the implementation of contingency plans, HCFA has not included the costs of implementing these plans in its budget estimates. HCFA will be developing the details of its contingency plans over the next few months and may include costs of implementation in future budget estimates.

Question. Has HCFA developed and executed end-to-end tests that include all systems involved in processing Medicare claims? Do these tests involve providers of services and financial institutions?

Answer. HCFA's end-to-end testing requirements includes testing that fully exercises all hardware and software being used in the production environment under HCFA's control to process the Medicare work. HCFA is requiring contractors to test data exchanges with Medicare servicing banks and providers. Contractors are required to test with providers, to confirm successful submission of claims with a future date.

Question. How will HHS assure that the billions of dollars in Federal grant payments are not disrupted when the new fiscal year begins in October?

Answer. I consider it a priority that the payment of Federal grants will occur without disruption in fiscal year 2000. The HHS Federal grants payment system, the Payment Management System (PMS), operates as a centralized electronic payment system and fiscal intermediary between the recipient and the Federal grant awarding organization. HHS expects to have the existing legacy PMS certified as Y2K compliant and implemented by June 1999. A business continuity and contingency plan has been developed and will be tested by June. In addition, a replacement and reengineered PMS will be tested and available for implementation before the end of fiscal year 1999.

NURSE ANESTHETISTS

Question. I have heard from a number of constituents over the past several years regarding HCFA's Proposed Conditions of Hospital participation in Medicare specifically on the anesthesia related issue. When do you expect to finalize this rule, and what, if any, are the delays in the issuance?

Answer. The proposed rule was published in the Federal Register on December 19, 1997. The proposed rule received approximately 60,000 comments. More than 20,000 of the comments discussed physician supervision of nurse anesthetists. We have not set a date of issuance for the final rule.

STEM CELLS

Question. Madam Secretary, as you know, this subcommittee held three hearings on stem cell research (12/2/98, 1/12/99, and 1/26/99). On January 15, the DHHS issued a legal opinion that NIH could proceed with stem cell research, if the stem cells were derived with private funds. Dr. Varmus indicated that NIH will move to establish guidelines and procedural protections to assure that any stem cell research would be done ethically. What steps are now being taken in the aftermath of the issuance of the legal opinion?

Answer. NIH is in the process of convening a working group of the Advisory Committee to the Director (ACD) to develop guidelines that specify what work using these cells can and cannot be supported with NIH funds and to outline restrictions on the use of such funds in the derivation of the cells. The working group will also be asked to develop an oversight process for the review of research proposals which propose to conduct research utilizing these pluripotent stem cells. The working group will meet in public session and will be composed of scientists, clinicians, the lay public, ethicists, and lawyers; former members of the Human Embryo Research Panel may be asked to participate. NIH already has two thoughtful sets of guidelines which will inform these efforts—the 1994 Report of the Human Embryo Research Panel and the regulations regarding Research on Transplantation of Fetal Tissue (section 498A of the Public Health Service Act). Once developed, guidelines for research utilizing human pluripotent stem cells will be published in the Federal Register for public comment. The NIH will not be funding any research using pluripotent stem cells until guidelines are developed and widely disseminated and an oversight process is in place.

Question. On February 11, 1999, seventy Members of the House wrote to you regarding stem cell research, and on February 12, 1999, you received a similar letter from seven Senators. Both of these letters opposed the Department's legal opinion that would allow stem cell research to go forward. In your opinion, if stem cell research were not to go forward because of this opposition, would you regard this as a setback for public health? How soon could stem cell research be initiated with NIH funding? Is the intent of the Department to move ahead with NIH-sponsored stem cell research? If there is a substantial research and public health benefit to be derived from stem cell work, shouldn't the Department do all it can to see to it that NIH resources be committed as soon as possible?

Answer. It is essential that the Federal Government play a role in funding and overseeing the conduct of this research so that all scientists—both privately and federally funded—have the opportunity to pursue this important line of research. Federal funding will provide oversight and direction that would be lacking if this research were the sole province of industry and academe. We hope the guidelines and oversight process will be operational within the next several months.

MEDICARE MANAGED CARE PULLOUTS

Last fall, 50,000 Medicare beneficiaries lost their managed care options as the result of nearly 100 HMOs either cutting back on their service areas or terminating their government contracts.

Question. What impact did this have on beneficiaries? Were they forced to change doctors or did they lose prescription drug coverage?

Answer. No beneficiary lost Medicare coverage as result of these withdrawals. Beneficiaries who live in areas without managed care options (or those who have these options but don't choose to exercise them) receive their Medicare benefits through the original Medicare program. HCFA does not collect information on specific physicians used by beneficiaries in managed care plans, so it is difficult to determine if they were forced to change doctors. However I want to note than many physicians who participate with Medicare + Choice plans also participate in the fee-for-service Medicare plan, so some beneficiaries may not have had to switch doctors. With respect to drug coverage, some of the beneficiaries who had drug coverage may have lost such coverage because the fee-for-service Medicare plan does not cover outpatient prescription drugs. Others may have purchased a Medicare supplemental policy that covers drugs.

I would also like to note that some of the 50,000 beneficiaries who lost their managed care option as a result of the pullouts now have a managed care option available. In two of the counties where there were no managed care options available

to Medicare enrollees of terminating plans, new or expanding Medicare + Choice organizations now provide managed care choice. Those counties are Monroe County, Florida (Beacon Health Plans) and Muskigum County, Ohio (Health Plan of Upper Ohio Valley).

Question. How do you explain this exodus of Health Maintenance Organizations from Medicare?

Answer. There were several factors influencing Medicare + Choice (M + C) plans' decisions to withdraw from the Medicare managed care program. I would like to tell you about those factors, but I would also like to tell you about what the administration is doing to help beneficiaries affected by the withdrawals.

The American Association of Health Plans asked HCFA in September to allow plans to revise their adjusted community rate (ACR) proposals. HCFA told the Association that we would not allow revisions to the previously approved ACRs because many beneficiaries would receive fewer benefits than they would have absent the revision while, at the same time, paying more for their health care.

BBA changes in HMO payment rates and contracting standards have been blamed for the recent plan terminations and service area reductions. While the BBA changes may have been a contributing factor, the upheaval in the Medicare market comes at a time of change for the entire HMO industry. The majority of HMOs are suffering financial losses, or experiencing reduced profitability in all lines of business and organizations are re-evaluating business decisions made in earlier times when different circumstances prevailed. As an example of market changes on the order of those in Medicare managed care, 20 percent of participating HMOs dropped out of the FEHBP program at the end of 1998 (although not many FEHBP enrollees were affected by the pull-outs).

The recent upheaval in the Medicare market is not unprecedented. It is reminiscent of similar upheaval in the Medicare risk program in the late 1980s, when what was then an essentially new program turned out to be an unattractive market for many HMOs.

With respect to those areas not currently served by a Medicare managed care plan, the President recently announced a new policy to expedite the approval of health plans applying to enter markets without Medicare managed care plans. HCFA is working hard to speed up its review and approval of plans seeking to enter markets without Medicare managed care options. HCFA is giving these applications first priority for review and will expedite their entrance into the market as long as they meet the solvency, quality, and other standards necessary to protect beneficiaries.

HCFA has also reduced administrative burdens for M + C plans. For instance, on February 17, HCFA issued a portion of the M + C final rule which reduces several administrative burdens dealing with provider participation, health assessments, termination notices, coordination requirements, and other areas. Additionally, HCFA will issue a comprehensive final rule this fall that will give further consideration to reducing these burdens. The final version of the Quality Improvement System for Managed Care (QISMC) substantially reduced the number of its requirements, particularly reducing the number of quality improvement projects from 13 to 2 per year. HCFA has also extended the time period for implementation of these projects, and are working with M + C organizations to implement the compliance requirements for the new regulatory and QISMC provisions over an extended time period.

Finally, the President's budget package proposed that the deadline for adjusted community rate proposals be extended from May 1 to July 1. This will enable M + C organizations to develop more informed estimates of their costs than they were able to produce last year.

Question. Your budget proposes increasing fees assessed managed care plans with Medicare plus Choice contracts from the current level of $95 million to $150 million. Isn't this likely to further deter health plans from operating Medicare managed care programs?

Answer. As I stated earlier, we know that M + C organizations are unenthusiastic about user fees, but we have seen no evidence that the fees have either caused plans to leave the Medicare program or dissuaded potential applicants from joining the program. Note that in 1998, the $95 million user fee amounted to about half of a percent of the premium HCFA pays to Medicare + Choice organizations. In 1999, due to an increase in overall program expenditures, $95 million amounts to about a third of a percent. Should the 2000 appropriation reach $150 million, it will return to the 1998 impact—more than a third, but probably still less than half of a percent of the premium. Therefore, after accounting for increased Medicare payments to M + C organizations, the impact of a $150 million user fee in 2000 will be about the same as the $95 million user fee was in 1998.

We have concluded that, because the impact is relatively the same in 1998 and 2000, organizations' behavior concerning participation will be relatively the same—new applicants will not withdraw their applications because of a increased user fee, and existing plans will not leave the program because of an increase.

QUESTIONS SUBMITTED BY SENATOR TED STEVENS

HEALTH CARE FINANCING ADMINISTRATION (HCFA) YEAR 2000 COMPUTER COMPLIANCE

As the nation's largest health insurer, Medicare expects to process over a billion claims and pay $288 billion in benefits annually by the year 2000. The consequences of its systems not being Y2K compliant could be enormous. In September 1998, GAO issued a report that concluded that HCFA and its contractors were severely behind schedule in addressing the Year 2000 issue for its Medicare claims processing systems. According to GAO, HCFA has spent $606 million to address the Y2K problem and plans to spend an additional $330 million for Y2K contingencies.

Question. With close to $1 billion budgeted and grave concerns that its systems will not be compliant by January 1, 2000, how does HCFA plan to ensure that all Medicare claims are processed and that all eligible participants receive their benefits?

Answer. Just to clarify, HCFA's current Y2K budget and spending estimates are approximately $606 million. This estimate includes the estimated $168.4 million obligated in fiscal years 1996 through 1998 to support Y2K activities. This estimate also includes the agency's fiscal year 1999 budget estimate of $287.6 million and its fiscal year 2000 budget request for $150 million to support Y2K efforts.

HCFA is confident that the Medicare claims that reach our systems will be processed correctly and that records of payments will be sent to providers and the banking system. Remediating provider systems so that they can produce and send claims, and ensuring that the providers bank can receive and process payment is beyond HCFA's responsibility and resources.

However, we are engaged in a very proactive outreach effort to make providers aware of what they need to do, and to provide information and tools to assist efforts to renovate and test. Further, we have alerted providers that they must be able to submit electronic claims in a Y2K compliant format in order to be paid for the services they render. We have notified providers, physicians and suppliers that they must begin submitting electronic claims in the Y2K compliant format as of April 5, 1999. Failure to submit claims in this format will result in the return of the claim to the provider without processing it for payment. We view this as a powerful incentive for providers to work toward compliance.

Question. Has HCFA developed a program to assure that Managed Care Organizations will be Y2K compliant and have business continuity and contingency plans in place this year?

Answer. HCFA has taken a number of actions to ensure that its Medicare managed care organizations (MCOs) are Y2K ready. HCFA included in its 1999 contracts with Medicare + Choice plans and other risk plans a provision that requires the plans to become Y2K ready. The agency has also provided its compliance definition and testing guidelines to MCOs and has notified MCOs that they are required to certify their Y2K readiness as of March 31, 1999. We are also planning to conduct a series of conferences for MCOs to discuss HCFA's Y2K readiness requirements in March and April of 1999.

The agency will be acquiring the services of an independent verification and validation (IV&V) contractor to assess the risk associated with MCO certifications and conduct on-site review of MCOs judged to be at high risk. MCOs whose on-site reviews reveal deficiencies will be required to submit corrective action plans. Corrective action plans will be reviewed by the IV&V contractor and, possibly, be re-visited for verification and validation.

We believe it is also important for MCOs to recognize the risks associated with the Y2K problem and develop contingency plans. HCFA has notified MCOs to begin Y2K contingency planning, submit their contingency plans to HCFA for review, and submit monthly progress reports on their contingency planning efforts.

Question. On February 3,1999, $93.4 million in emergency appropriations were released to HCFA. Do you expect that you will be requesting additional funds from the emergency fund?

Answer. At this time, we believe our latest budget estimates will support the Y2K funding needs of the agency. We plan to continue to update our budget estimates as the Y2K project evolves. Should we encounter additional funding needs, such as

funding to support the implementation of contingency plans, we will go through the establishment process and work with the Congress to obtain the required funding.

MEDICAL DEVICES, PROCEDURES AND DRUGS

Within your Department the Food and Drug Administration has the responsibility to determine the safety and efficacy of new medical treatments, devices and drugs. The FDA's process for approval is rigorous and well-defined. It is considered the "gold standard" for the world. Once the FDA has determined that a medical treatment, diagnostic procedure, device or drug is safe and effective for labeled indications, that approval generally acts as a "green light" for the private insurance market to begin paying for that service or medication.

Question. What is being done to assure that Medicare beneficiaries have equal and timely access to the latest technology?

Answer. A revamped process for making Medicare's national coverage decisions has been and remains among my highest priorities. Our new process will be responsive, open, and participatory—ensuring that we have the views of not just the best medical and scientific resources in the Nation, but also that we hear from a wide range of concerned parties, including consumers and the industry. This process will be published in the Federal Register this summer. We review an issue as soon as there is sufficient evidence of its medical effectiveness, even if only for a limited use. In order that we and the medical and research communities remain in contact, we have always been willing to meet with researchers prior to design of clinical trials or other research to ensure that they understand the amount and type of information we usually require in order to make a national coverage decision. This helps us move quickly and effectively to review new procedures and technologies.

In fact, several of our most recent national decisions dealing with some of the most contemporary developments in technologies and procedures (transmyocardial revascularization, cryosurgery of the prostate, cardiac monitoring by bioimpedence) have involved services about which we offered suggestions as to the amount and kind of information that could lead to a positive coverage decision. In such cases, the parties' willingness to work with us, consider the advice, and produce information timely enables us to make decisions in a very short time. Further, we are working right now with the Food and Drug Administration to examine ways in which both agencies can work together to share information with interested parties to increase their awareness of our roles and requirements, and to help facilitate the review process.

Question. Specifically, does Medicare have an expedited coverage determination process for breakthroughs with respect to medical devices, procedures and drugs?

Answer. We do not have a separate, fast-track process. I am confident that our revamped process for making national Medicare coverage decisions will be able to respond in a timely manner when such issues arise. Our work in assembling the best clinical, scientific and other experts, as well as qualified representatives of consumers and the industry, as the backbone of our new Medicare Coverage Advisory Committee, will enable us to respond to these issues with the baseline of solid, evidence-based policy and decision making as our number one consideration. Our work with the Food and Drug Administration to move toward better public understanding of our respective roles and requirements and to facilitate our processes with mutual efficiency will also contribute to our ability to be aware of and prepared for fast-moving issues and to respond effectively. We are considering how we might develop a process, for example, that would channel parties to HCFA at an earlier point in their work with FDA, so that we can apprise them of the informational requirements for Medicare coverage and other issues.

RURAL HEALTH AND USER FEES

The budget proposes to collect $55 million in user fees from doctors and other providers of Medicare services by imposing a $1 penalty on any reimbursement claim which is not submitted electronically.

Question. Wouldn't this primarily target doctors in rural communities who may not have the resources to purchase the necessary computer equipment?

Answer. No. Providers, regardless of location, who currently do not have computer equipment, or do not have the resources to purchase computer equipment, can request a waiver of this fee. The Administration's legislative proposal gives providers the option to request a waiver based on their not having, or not being able to afford, the necessary computer equipment.

Question. What would a hard-pressed rural doctor have to do to obtain an exception from this user fee?

Answer. Providers would need to request a waiver from the fee indicating the reason, e.g. they do not possess, or cannot afford, the required computer equipment, or they do not submit a sufficient number of Medicare claims to warrant purchasing the necessary computer equipment.

QUESTIONS SUBMITTED BY SENATOR JON KYL

SECTION 1115 WAIVER

I understand through John Kelly, Director of the Arizona Health Care Cost Containment System (AHCCCS), that the Department of Health and Human Services has recently approved a year extension of the state's Section 1115 waiver to operate our Medicaid program. As you know, this extension enables the state to operate under the existing terms and conditions of the 1115 waiver. Arizona has operated under 1115 waiver authority since the inception of the AHCCCS program in 1982. During this time, AHCCCS has been a national leader in delivering quality care in an efficient manner. In fact, in a recent study, AHCCCS was rated as one of the three most efficient Medicaid programs in the nation. (Citizens for a Sound Economy study, 1997.) While the one year extension is certainly appreciated, the AHCCCS program is unclear whether all the provisions of the Balanced Budget Act of 1997 will be applied to the state program in two to three years, or whether the waiver authority will exempt AHCCCS from some of these provisions. Arizona is concerned that all of the provisions in the BBA will apply when they seek a renewal of their waiver in one year.

Question. Madame Secretary, how does the BBA affect existing 1115 waivers and the renewal process?

Answer. The BBA contains a limited exemption from new managed care requirements for waiver programs under section 1115 and 1915(b). Specifically, section 4710(c) provides that none of the provisions contained in sections 4701 through 4710 of the BBA will affect the terms and conditions of any approved waiver under section 1915(b) or 1115 of the Act, as the waiver stood on the date of the BBA enactment—August 5, 1997. We believe that this provision was intended to give States some flexibility in how the BBA would impact their approved waiver programs and provide time for States to come into compliance with new requirements. The provision exempts section 1115 and 1915(b) waivers only from those BBA provisions regarding Medicaid Managed Care contained in Chapter 1 of Subtitle H of the BBA. It specifically did not apply to other chapters or provisions contained elsewhere in the Act.

The extent to which a State's approved 1115 waiver program will not be required to come into compliance with these new requirements will be determined by several factors. In general, any provision of a waiver program that is specifically addressed in the State's waiver proposal, statutory waivers, special terms and conditions, operational protocol, or other official State policy or procedures approved by HCFA as of August 5, 1997, would not be affected by the BBA provisions (even if it differs from the BBA managed care requirements) as long as the waiver in effect at that time is in place.

Further, section 4757 of the BBA amended section 1115(e)(2) of the Act to permit a specific 3-year extension of 1115 waiver authority for certain statewide, comprehensive health care reform programs, under "the same terms and conditions . . . that applied to the project before its extension under this subsection." 1115 demonstrations that qualified under this provision would therefore maintain their exemptions from the BBA provisions in the 3-year period granted for an extension under this authority. However, several States (including Arizona) do not meet the requirements for a 3-year extension under this authority. These either do not meet the time limits for submission of an extension request that were in the BBA or are not statewide demonstrations. The BBA managed care provisions would apply to these programs as of the date their current section 1115 authority expired. However, the BBA does not preclude waivers of specific requirements nor preclude permitting Federal financial participation for costs not otherwise matchable in these instances. These determinations would have to be made on a State by State and provision by provision basis.

Arizona's experience in their recent 1-year extension is an example of how this process will work. The State wanted to maintain its enrollment/disenrollment process, which differs from that in the BBA. Arizona requested continuation of its waiver of section 1903(m)(2)(A)(vi), which contains the enrollment/disenrollment requirements, and after consideration, this waiver was granted.

Question. Is it your intention that in three years all Section 1115 waiver states must comply with all provisions in the BBA, or must renegotiate their 1115 waivers?

Answer. With respect to States that are granted 3-year extensions under section 4757 of the BBA, we are not yet clear on how the continuation of these demonstrations and exemptions from BBA requirements are to be addressed when the 3-year extensions expire.

Question. If states must renegotiate their waivers, will HCFA be willing to waive some provisions of the BBA to allow states to continue operating their programs?

Answer. The Secretary may consider waivers if the Secretary determines the program meets or exceeds the beneficiary protection standards of the BBA. As with Arizona's recent experience, a determination will have to be made on a provision-by-provision basis, balancing the beneficiary protections and other provisions in the BBA against the state's policies and procedures in its demonstration and the need for flexibility in administering the program.

QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

TOBACCO

The President announced in his State of the Union address that the Federal government will proceed with a suit against the tobacco industry for tobacco-related costs in Federal health programs, including the Medicare program.

Question. To what extent is HHS working with the Department of Justice in preparing the suit, and what is the Administration's time frame for moving forward?

Answer. The Department of Justice is forming a task force to prepare to litigate to recover these costs. The task force will file the lawsuit when the preparatory work has been completed; they will be working to bring appropriate suits as soon as possible. We have met with the Department of Justice on this, and supplied legal and factual material. We plan to assist Justice as needed over the course of the work of the DOJ Task Force.

As you know, the Governors are in town this week and one item at the top of their agenda is the fate of the $195 billion settlement the states reached last year with the tobacco industry. I believe that because the state suits were based on Medicaid recovery, the Federal government has the right to collect its share of those Medicaid costs. Therefore, I was pleased to see that the President's budget assumes a Federal share of 57 percent (the average Medicaid matching rate) of those funds.

Question. However, recovering the Federal share is not going to be easy here in the Congress. It is critical that the Administration take a tough line. Do you intend to take a tough line, and if an agreement is not reached with the states, will HCFA withhold the Medicaid dollars?

Answer. Thank you for supporting our collection efforts. As you know, current Medicaid law requires HCFA to recoup the Federal share (on average 57 percent) of all State third-party liability collections, including the recent State tobacco settlements. Since US taxpayers paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes that the Federal government will follow the law and claim its share of the proceeds.

The Administration supports legislation that would enable States to retain these funds in exchange for making a commitment that the Federal share of the settlement's proceeds will be spent on shared national and State priorities: to reduce youth smoking, protect tobacco farmers, improve public health, and assist children.

It is for this reason that the Administration has delayed action on claiming the Federal share of the State tobacco settlements until fiscal year 2001 so that we can work with the States and Congress over the next year on mutually agreeable legislation.

QUESTIONS SUBMITTED BY SENATOR HERB KOHL

As you may recall, at last year's hearing I spoke with you about my legislation to require criminal background checks for long-term care workers. Since then, I have been pleased to work with you on this initiative, and am glad to see that background checks for nursing home workers were included in the budget. However, I feel strongly that it is equally important to require checks for all long-term care workers. After all, it does little good to stop a criminal from working in a nursing home if they can then go on to work in a home health care agency.

Question. Why did the Administration stop short of requiring checks for all long-term care workers? Would you support an expansion of the background check to other long-term care settings?

Answer. HCFA's statutory authority limits the types of settings it may regulate. It does not have authority to regulate some settings that are considered long-term care, e.g., adult residential care, assisted living and similar settings. We understand there has been marked growth in the number of these long-term care settings, including home health agencies, over the last several years. As such, we will evaluate expanding background checks to other long-term care facilities that participate in Medicare and Medicaid.

We believe that the Nation's elderly need reasonable safe-guards when they are living in settings that provide personal, supportive and medical care. While we wish to ensure that no care giver with a criminal past be a care giver to a person who may be cognitively and physically dependent, we believe it may be more constructive if we first take several intermediate steps before the introduction of legislation requiring background checks of all workers:

Evaluate the effectiveness of the fiscal year 1999 appropriation provisions to establish within the Department of Justice a voluntary process that would permit nursing home operators to query the FBI database for criminal background checks.

Develop a national criminal abuse registry, as proposed in the President's Budget and assess how it may be expanded beyond nursing home employees.

Determine the number of individuals impacted by legislation requiring people working in long-term care to have a criminal background check. This includes agreeing on the settings that would be part of the definition of long-term care.

Question. As I'm sure you are aware, nursing home operators are concerned about the costs of these background checks. Do you believe that the benefits of conducting checks outweigh the costs? What steps do you think can be taken to minimize those costs? Would the Administration be willing to consider proposals to divide the costs between the nursing facilities and the government?

Answer. HCFA believes that these background checks are an important part of our goal to better protect the Nation's elderly. In addition, the background checks should reduce the nursing homes' vulnerability to costs from litigation. We also believe that this initiative is cost-effective and should be included as a price of doing business for nursing home operators. User fees are a method of encouraging providers to internalize the costs of activities that are crucial to the proper functioning of the program. In some cases, such as criminal background checks, the cost of the activity also benefits the provider's private sector business. Because we recognize the costs involved, we have proposed in legislation to limit the amount of the fees to the lesser of the actual cost of the background check, or $50.

Private sector companies engage in many forms of risk mitigation, such as checking the credentials of professional staff and bonding those with financial responsibilities. The Government has never entered into an arrangement of sharing costs for such activities, and we believe that this proposed requirement should not be an exception.

As you know, last July, the Aging Committee held a hearing about serious problems of malnutrition and neglect in some California nursing homes. As a result, the Administration has significantly stepped up their oversight of nursing homes, and your fiscal year 2000 budget calls for $203 million for inspection activities. However, some of that increase is paid for with user fees.

Question. In the event that Congress again rejects such user fees this year, does the Administration still intend to pursue this increase? How will it be paid for?

Answer. Unlike last year, HCFA's budget request this year is not reduced by the amount of the proposed user fees. The Administration is proposing that for any user fees that are enacted, HCFA's requested program management funding level would be reduced by the amount estimated to be received from such enacted user fees. Therefore, HCFA's request assumes funding sufficient to effectively administer its program whether the users fees are enacted or not.

The fiscal year 2000 budget includes $1.2 billion for the Child Care & Development Block Grant. However, there is growing evidence that there is a real shortage of child care for infants and toddlers ages 0–3, and that care for these younger children in considerably more expensive.

Question. What plans does the Administration have to meet this need? Do you agree that we should expand the infant and toddler set-aside in the Block Grant as part of this effort?

Answer. We have asked for an additional $1.155 billion in fiscal year 2000 to expand the availability of subsidies to working families. States would have the flexibility afforded them under the CCDBG Act to direct the use of these funds, for example, using them to pay higher rates to infant and toddler providers.

In each of the last 3 years Congress has earmarked $50 million specifically for activities to increase the supply of quality care for infants and toddlers. States have been especially appreciative of this targeted funding as it has allowed them to address the critical need they face for this care. We favor any initiative that increases the availability of quality child care for infants and toddlers.

In the fiscal year 2000 budget, we have requested the $50 million earmark for quality care for infants and toddlers. This reflects our continued commitment to quality care for infants and toddlers and to giving States the flexibility to meet their individual supply shortages.

Additionally, the Administration has proposed an Early Learning Fund (ELF) of $600 million in fiscal year 2000 for the specific purpose of purposes of improving the quality of child care for children under age 5 and of promoting the healthy development during a child earliest years.

I am very concerned that the Long-term Care Ombudsman program continues to be severely underfunded. The Ombudsman is often the first person a family contacts for help when someone is abused or neglected in a long-term care facility. They work as advocates for these families to make sure that abusive and neglectful situations are corrected. Although we managed to provide a $3 million increase for the Ombudsman for fiscal year 1999, that is still insufficient to meet these needs.

Question. Why has the Administration decided to level fund this vital program again this year?

Answer. We agree that the patients in long-term care facilities should be assured that the services they receive are of the highest quality. Poor performing homes need to know that corrections must occur. The Ombudsman program is part of a major Department initiative to strengthen performance in nursing homes. HCFA will expand State inspection and enforcement efforts, establish a national patient abuse registry, and improve Federal oversight of State surveyor activity. We will also be seeking legislation to require nursing homes to conduct criminal background checks of employees. The Department will also be establishing a "Nursing Home Compare" website that residents and their families can use to compare the quality and safety record of nursing homes in their area.

In fiscal year 2000, we intend to sustain the increased funding level of $12.2 million provided by Congress this past year for the Ombudsman program. The tight discretionary spending caps have forced us to make very limited program expansions. For the Administration on Aging, we are proposing a new National Family Caregiver Support Program and seeking expansion of the home-delivered nutrition services. One of the objectives of the new Caregiver Program is to maintain frail older persons in their homes for longer periods.

QUESTIONS SUBMITTED BY SENATOR DIANNE FEINSTEIN

FEDERAL MEDICAL ASSISTANCE PERCENTAGE

The Federal medical assistance percentage rate for California, as for other states, is based on a per capita income using a Census Bureau estimate of the state's population. However, Governor Davis believes the Census Bureau's numbers undercount the state's population, which results in an overestimation of California's per capita income and a subsequent lowering of California's FMAP rate. According to the Governor, the state Department of Finance keeps more accurate records relying in part on driver's license change of address data, which is current through November 1998. The Census Bureau relies solely on tax returns, which are current only through the first quarter of 1997. For example, of the three major drivers of population change—births, deaths, and migration, the primary area of discrepancy is migration. For a period of 1990 through 1998, the Census Bureau estimates a net out-migration of more than 13,000 while California's data indicates a net in-migration of more than 755,000.

Question. I think that we can all agree that the more accurate data is the best. What steps can the BHS take to use more accurate data, such as that generated by the Department of Finance, in determining the FMAP for California's Medicaid program?

Answer. No one can disagree with the statement about accurate data. We all prefer accurate data. The law requires, however, that HHS use the per capita state incomes as generated by the Department of Commerce. Commerce (Census) has decided (and the decision has been upheld by the Supreme Court) that it will not use numbers adjusted for the Census undercount for calculating per capita incomes or for any other use involving the distribution of Federal funds.

Discussion

The major contribution of the data generated by the Department of Finance is that they use the estimates of the undercount in the 1990 Census to decrease the average incomes of each State and they feel they have more accurate data on immigration than Census provides. Since the undercount tends to include a concentration of minority populations, those states with large concentrations of minorities should do better if adjustments are made. Of course, better information on immigrants will also benefit those States with large immigrant populations.

A 1992 Census decision, published on January 4, 1993 and later upheld by the Supreme Court, however, says that for distributions of Federal funds, the Census population numbers unadjusted for undercount must be used. The decision was reached after considerable research, public comment, and discussion. In spite of a large majority of public comments in favor of using adjusted data for disbursement, Census (and the court) decided not to use adjusted numbers for disbursing Federal funds. The deciding arguments seemed to be that:

The estimated undercount was small (on the order of 1.6 percent nationwide) and to make the adjustment for States might improve the accuracy, but for small areas the adjustment would probably not improve the accuracy of the resulting population numbers and the resulting distributions of funds. Because they felt that consistency was important, they did not adjust State numbers either. To do otherwise would be to violate that decision. Similarly, to use State data on immigration would violate the decision and would violate current law.

HHS has very little discretion about how it calculates the FMAP. Section 1905 (b) of the Social Security Act requires that HHS use the average incomes as calculated by the Department of Commerce and that those average incomes be used in a very specific way to calculate the FMAP. To change the FMAP calculation would require Congressional as well as executive action to amend the Social Security Act. In addition, (depending on the change) changing the FMAP might require overturning the 1993 Census decision referred to above.

Still, HHS is always willing to discuss any effort to improve the payment methodology for Medicaid expenditures and to cooperate with Congress to enact a better methodology into law.

Two parent work requirements under welfare reform.—In December, HHS announced that California failed to meet its two parent work requirement under welfare reform for two parent families. Only 24.5 percent of two parent families in California met the work requirement, as opposed to the 68 percent required by law. Sixteen other states and the District of Columbia also failed to meet the requirement. HHS has penalized California $7 million this year for failure to meet the requirement. The state is preparing a request that the penalty be waived, primarily because California had not fully implemented welfare reform in fiscal year 1997.

Question. How is HHS disposed to view requests for penalty waivers from California and the other states that failed to meet the two parent work requirement under welfare reform?

Answer. HHS is currently reviewing requests for reasonable cause exceptions from the work participation penalty from California and other States that failed to meet the minimum two-parent participation rate. We are considering all such requests carefully. As the statute provides, we will not impose a penalty against a State if we determine that it had reasonable cause for failing the two-parent rate. If we find that a State did not have reasonable cause, we will work with that State to develop a corrective compliance plan to rectify the problem. We do not impose penalties against States that achieve compliance under an approved corrective compliance plan. For any State that remains subject to a penalty, we will be reducing the amount of its penalty liability based on the degree of non-compliance, as required by the statute.

Question. Will most states be able to get the penalties waived if they develop plans to employ more two parent welfare families?

Answer. The law permits a State to submit a corrective compliance plan that outlines how the State will correct the violation and how it will insure continuing compliance with the requirements. If we accept a State's plan and it fully corrects the violation within the time period specified in the plan, then we do not impose a penalty on the State.

A plan to employ more two-parent families would be a natural element of correcting a violation of the two-parent participation requirement. However, we expect States to submit corrective compliance plans that fully address their compliance issues, including identification of measurable outcomes to be achieved within a specified period of time.

Question. Do you feel that the failure of 17 states to meet the two parent work requirements says about the appropriateness of the requirement?

Answer. The fiscal year 1997 participation rates reflect the very earliest period of implementation of the new welfare program. They are based on no more than one quarter's performance for any State. It would be premature to judge the appropriateness of the participation goals based on these limited and early data. Moreover, efforts in working with two-parent families vary greatly from State to State.

The Administration continues to encourage States to make the investments necessary to work with all families on their caseload, especially two-parent cases, and to use all available Federal and States resources.

Question. In other words, are we asking states to meet unattainable goals?

Answer. Given that nearly half of the States subject to the requirement for fiscal year 1997 met the two-parent participation rate, we cannot say that the goals are unattainable. While they are clearly very demanding, caseload reduction credits play a significant role in reducing the target two-parent rates to more attainable levels.

Adequacy of federal child care funding for families on welfare.—Under current Child Care and Development Block Grant (CCDBG) levels, California receives $333 million annually, enough to fund 79,000 child care slots each month. The State puts over $1 billion annually of its own money into child care for children on welfare. But there are 1.13 million children on welfare in California. Existing funding is not sufficient to place all of these children in child care so that their parents can leave welfare for work.

Question. By HHS' own estimate, child care funding in the Child Care and Development Block Grant serves only 10 percent of eligible children. In California, there are 1.13 million children on welfare, but only about 79,000 per month receive child care subsidies from the CCDBG. How can the Administration realistically expect states to move people from welfare to work when no affordable child care is available for their children?

Answer. This question points to a very real need—not only for additional subsidy funds—but for funds for capacity building to ensure that families moving from welfare to work have access to safe and affordable child care. We know also that many States make difficult choices in designing child care programs and have to juggle priorities. Due to scarcity of funding, many States put TANF children in the top priority of children to be served under the CCDBG. It is even more difficult for States to address the needs of working poor families.

For TANF families, States can use TANF funds for child care subsidies in addition to CCDBG funds. While we do not have figures on the numbers of children receiving child care through the TANF program, California has reported significant direct TANF expenditures on child care in fiscal year 1998—over $71.5 million. California also transferred $100 million in TANF funds to the CCDBG in fiscal year 1998. And although our data is not complete yet, we agree that numbers point to the need for additional CCDBG subsidy funds and resources to build capacity in the future.

By our latest estimates in fiscal year 1997, some 1.25 million children in the U.S. were served by subsidies from the funds governed by the Child Care and Development Block Grant. Under President Clinton's initiative, by fiscal year 2004, we hope to serve some 2.4 million children under the CCDBG Act. This is still far short of the approximately 10 million children we estimate to be income eligible for the CCDBG.

Question. Can you describe in more detail the President's proposal for a new Early Learning Fund?

Answer. The proposed ELF will assist States and localities in promoting quality child care, early childhood development, and early learning for children under the age of five.

Services will be delivered at the community level based on a community needs assessment. States would provide challenge grants through a competitive grant process to their communities. Each community would develop approaches to enhance the quality of child care for young children using selected benchmarks, national accrediting organization standards, and locally tailored goals. Not less than 70 percent of the funds would be used to serve low-income communities.

In keeping with this principle of community involvement, the following kinds of activities, which research show are important for quality, could be undertaken with these funds:

Parenting Education.—using Even Start, community based resource centers, home visiting programs, family literacy centers, preschools/schools, etc.

Information and Referral.—initiatives to develop/increase consumer education information/referral services that assist parents locate and assess the quality of child care services.

Family Child Care Networks.—reating/sustaining family child care networks that connect home-based providers to quality child development education and support.

Provider Training.—training child care providers on basic child development training, first aid, CPR, etc, as determined by local needs assessment.

Improving Staffing Ratios.—increase staff/child ratios, reduce group size.

Licensing/Accreditation Assistance.—helping child care providers meet State/local licensing and accreditation standards.

Standards Enforcement.—increasing the numbers of qualified licensing and standards enforcement staff and activities to improve monitoring and enforcement of State and local health and safety standards.

Health Services.—linking child care providers to health professionals and linking children to health care services, including mental health services.

Care for Special Needs Children.—supporting the inclusion of young children with special needs, increasing the quality of their care.

Salary/Benefit Enhancements.—assisting programs to increase their quality and continuity of care by retaining highly qualified staff.

Performance measures of the goals to be achieved through ELF activities will be established in consultation with localities. In summary, the ELF will provide States and communities with the resources to build on existing approaches—or locally identified needs—that will support school readiness in child care.

Question. How similar is this proposal to the grants to Local collaboratives program outlined in S. 17, the Child Care ACCESS Act, a bill that I am co-sponsoring?

Answer. We are very pleased that you and your Democratic colleagues introduced S.17 which provides meaningful assistance to help low-and middle-income families find and afford quality child care. The activities under S. 17 and our proposed Early Learning Fund are very similar in their purpose of involving communities in improving the quality of child care and early childhood development for our youngest children. For example, S. 17 provides for "activities designed to strengthen the quality of child care for young children and expand the supply of high quality child care services for young children". Our proposal specifically mentions "provider training, improving staffing ratios, licensing and accreditation assistance, standards enforcement, and salary and benefit enhancement"—all of which could also be seen as allowable activities under S.17. Furthermore, both proposals place an emphasis on serving low-income areas.

There are some differences between the two proposals in how assistance is delivered between the State and communities, as well as in the cost-share structure between the Federal and State partners. Despite these differences, both proposals would make essential investments seek to enhance the quality of services for young children.

HEALTH RESEARCH CUTS

The fiscal year 2000 budget proposes only a 2.1 percent increase for NIH. Congress increased NIH by 15 percent last year. The Cancer March (September) Research Task Force has recommended that the National Cancer Institute's budget be increased to $10 billion over the next 5 years (The fiscal year 2000 proposal is $2.7 billion, up $65 million or 2 percent).

Question. Doesn't an up-and-down budget, a yo-yo budget, discourage scientists from pursuing research, young scientists from being researchers?

Answer. While avoiding the up and down on the NIH budget would be desirable, the President had enormous restraints on his overall budget. Still, the President's request of $15.9 billion for NIH represents a 17 percent increase over two years for medical research and keeps NIH on path for a nearly 50 percent increase over five years. With the fiscal year 2000 funds, NIH plans to support a record total of nearly 30,000 research project grants. This includes over 7,600 new and competing awards, which while less than in fiscal year 1999, still represents the second highest annual total in history. The President has also committed to increasing resources for NIH medical research by nearly 50 percent over the next five years. The levels of resources available in both fiscal year 1999 and fiscal year 2000 should provide ample opportunities for bright, young scientists to begin to make their mark in the medical research arena. In fact, Dr. Harold Varmus, the Director of NIH, has indicated that within the 2.1 percent increase proposed for NIH for fiscal year 2000, NIH is committed to ensuring that the number of new investigators does not erode. We would welcome young scientists joining with NIH to help spend some of our requested $15.9 billion in advancing our knowledge of what causes diseases, such as cancer, AIDS, and diabetes; and discovering how to diagnose them earlier and more accurately, treat them successfully, and ultimately, prevent their occurrence in the first place.

Question. Commendably, you are proposing that Medicare cover routine patient costs of participating in cancer clinical trials. Now, only 2 percent of cancer patients participate. Won't this funding level mean a loss of resources for training and conducting those trials?

Answer. Within the $15.9 billion requested for fiscal year 2000, NIH expects to spend nearly $512 million in direct research training programs, about $1 million more than in fiscal year 1999. This will support a cohort of 15,693 research trainees. NIH continues to regard clinical trial research as a priority. NIH expects to provide nearly $1.6 billion across all the Institutes and Centers for the support of clinical trials in fiscal year 2000. This is an increase of over $49 million, representing a 3.2 percent increase over fiscal year 1999, compared to the total NIH increase of 2.1 percent. Clinical trials by just the National Cancer Institute are expected to grow by 2.4 percent in fiscal year 2000, to a funding level of $474 million. In addition to NIH resources, the fiscal year 2000 President's budget for the Health Care Financing Administration proposes to begin in fiscal year 2001 a three-year, $750 million demonstration project to cover the costs of patient care for Medicare beneficiaries who choose to participate in selected cancer clinical trials.

Cancer Research Coordination.—Some cancer researchers say that within NIH and in fact within the Federal government there is little to no coordination of cancer research. In NIH there are several institutes and government wide, there is, for example, Centers for Disease Control, the Veterans Administration, the Defense Department.

Question. How does NIH coordinate among NIH institutes and among all agencies to government to (1) avoid duplication in research and (2) to close gaps in areas that are receiving inadequate attention?

Answer. While the National Cancer Institute (NCI) generally has the lead within the Federal government on most cancer research, many research questions of interest to NCI deal with issues that are also related to the mission of other NIH institutes and other entities within the Federal government. In order to avoid duplication and to help ensure that proper attention is provided to all promising areas, NCI is engaged in many efforts of collaboration and coordination with other Federal agencies.

Interagency coordinating groups.—One of these efforts is to organize or participate in specific interagency coordinating groups. For example, in the area of environmental cancer, NCI organized the Interagency Collaborative Group on Environmental Carcinogenesis over 17 years ago. Other members of this group include the National Institute of Environmental Health Sciences; the National Library of Medicine; the National Toxicology Program; the Centers for Disease Control and Prevention (CDC); the Food and Drug Administration (FDA); the Armed Forces Institute of Pathology; the U.S. Army Biomedical Research and Development Laboratory; the Consumer Product Safety Commission; the Department of Energy; the Department of Labor/Occupational Safety and Health Administration; the Department of Transportation; the National Institute of Standards and Technology; and the Smithsonian Institution. NCI and CDC, especially its National Center for Environmental Health, also have regular meetings to identify and evaluate areas for joint collaborations.

CDC also participates in funding with NCI the National Cancer Policy Board. This board has been established by the National Academy of Sciences to bring together constituencies concerned about cancer control with those who conduct research and deliver health services. Given that cancer remains the second leading cause of death among women in the United States, NCI has been committed to the support of the goals and objectives of the National Action Plan on Breast Cancer (NAPBC), which unites the efforts of all HHS and other Federal agencies and private sector groups and is coordinated by the Office on Women's Health within the Office of the Secretary. Three senior NCI scientists serve on the NAPBC Steering Committee, and a number of NCI staff are active participants in the NAPBC working groups.

Research collaborations.—There are numerous examples of coordinated cancer research. For instance, NCI has a close working relationship with the National Institute of Allergy and Infectious Diseases, and the NIH Office of AIDS Research in coordinating research on AIDS and AIDS-related malignancies. CDC is also involved, along with the Department of Energy and the Nuclear Regulatory Commission, in NCI's ongoing studies related to the cancer-associated effects of the Chernobyl nuclear power plant accident and the nuclear weapons programs of the former Soviet Union. NCI and the CDC are also coordinating the preparation and storage of cell lines derived from the only relatively large, representative, population-based collection of blood samples of the U.S. population. This collection of cell lines is expected to significantly facilitate the evaluation of gene-gene and gene-environment inter-

actions in development of a variety of human diseases including, but not limited to cancer.

In radiation-related research, NCI and CDC's National Center for Environmental Health have a Memorandum of Understanding to highlight the respective roles of these agencies and identify specific approaches to coordinate activities. NCI, in collaboration with CDC and the Department of Veterans Affairs, is currently updating its radioepidemiologic tables. These tables, originally prepared by NCI, present data linking risk for cancer to exposure to radioactive materials, and are based on complicated calculations and risk assumptions. The Department of Veterans Affairs is requesting the update because the original tables date back to the mid 80's.

Cancer control.—One of the more prominent interactions between NCI and CDC is the noteworthy transition of tobacco control research to application seen in the transfer of the successful American Stop Smoking Intervention Study (ASSIST) research program in 17 States from NCI to CDC for full implementation across the nation. NCI also holds regular meetings with CDC's Office of Smoking and Health for the purpose of coordinating tobacco initiatives.

Cancer Surveillance.—NCI and CDC are both sponsoring organizations of the North American Association of Central Cancer Registries (NAACCR) which works toward coordinating population-based cancer registries, including NCI's Surveillance, Epidemiology, and End Results (SEER) Program and CDC's National Program of Cancer Registries. NCI is also working with CDC to determine how to add questions on health behaviors, screening, and health status to the 1999/2000 National Health Interview Survey Supplement, and discussions are ongoing on the use of other surveys in which NCI might be able to participate. NCI is providing support for a DNA repository that is being established as part of the CDC-supported National Health and Nutrition Examination Survey (NHANES) III. This repository will be available for studying genetic polymorphisms in about 1,000 people.

Cancer Education.—Several years ago, NCI began developing a Partnership Initiative for cancer education programs that includes agreements between NCI and other Federal agencies, voluntary organizations, and the corporate sector. For example, in a cost-saving partnership with the Food and Drug Administration, the Cancer Information Service (CIS), NCI's nationwide cancer information, referral, and outreach service, is providing callers with referrals to FDA-certified mammography facilities. The NCI is also partnering with CDC to insure the best utilization of Federal resources for breast and cervical cancer screening services provided by CDC through its State health department grantees. On June 15, 1996, the United States Postal Service issued a 100 million new breast cancer awareness stamps and launched a unique partnership with the Cancer Information Service. Each sheet included the CIS toll-free telephone number—1–800–4–CANCER. The effort also included coordinated community outreach efforts throughout the country to raise awareness about breast cancer and what to do about it.

NCI is also providing educational program support to the partnerships between NCI and the Department of Defense and the Department of Veterans Affairs to increase access to clinical trials. Since the Health Care Financing Administration launched its awareness campaign on Medicare coverage for mammograms, the CIS telephone service has also been alerting Medicare-eligible callers interested in mammograms to the HCFA benefits. NCI and CDC staff, in conjunction with the National Action Plan on Breast Cancer, are also collaborating on the development of genetic education materials, including a CD-ROM about genetic testing.

Cancer information dissemination.—Since 1995, NCI and CDC have collaborated on efforts to improve the access of underserved populations to the CIS through work with state health departments. The NCI and CDC also cooperate on the "5 A Day" Program, which seeks to spread the message that a diet rich in fruits and vegetables may help prevent cancer. The NCI offers supplements to CDC grantees to incorporate evaluation materials for the "5 A Day" activities in their States into their own projects. NCI and CDC also collaborated recently on an advertisement in Family Circle Magazine encouraging readers to consume at least 5 servings of vegetables and fruits per day.

Question. Do we need a better mechanism? When will we conquer cancer?

Answer. In 1971, Congress passed the National Cancer Act, increasing resources for cancer research and broadening the mandate of the National Cancer Institute (NCI), the principal Federal agency supporting and conducting cancer research. It created the National Cancer Program (NCP) to encompass the research programs of the NCI and relevant programs of other National Institutes of Health (NIH) institutes, centers, and divisions (ICDs), Federal agencies, and non-Federal organizations. The National Cancer Program has enabled a very active and wide ranging national program for waging war against this disease.

Coordination of the many activities that comprise the National Cancer Program calls for exchange of information, avoidance of overlap and duplication, support of the many areas of expertise needed to overcome cancer, and recognition and stimulation of research opportunities that lead to understanding the etiology and biology of cancer and thus provide the means to control and prevent it. NCI acts as the facilitator of this concerted effort against cancer.

As evidenced by the improving statistics for cancer incidence and mortality, we have made considerable progress in unraveling the mystery of cancer causation and developing some effective treatments. There is still much to be done and we look forward to a continuing strong effort to rid the nation of this disease.

Question. What do we need to do to conquer cancer?

Answer. NCI has stated that a three-pronged approach is necessary to achieve progress in conquering cancer which would: (1) sustain the proven research programs that have enabled us to come this far; (2) seize extraordinary opportunities to further progress made possible by our previous research discoveries; and (3) create and sustain mechanisms that will enable us to translate rapidly our findings from the laboratory into practical applications that will benefit everyone.

Progress is needed on many fronts and the Department is ready, within its available resources, to pursue all scientific opportunities as they arise. As examples of areas where additional progress is needed before cancer is likely to be conquered, it is important for scientists to determine the most effective age to begin cancer prevention programs related to risk factors such as tobacco use, sun exposure, and diet and nutrition. Increasing the access of the research community to recent advancements in mouse models of human cancer is also important to the fight against this disease, as is the need to expand access of patients to clinical trials to test novel approaches to the treatment and prevention of cancer.

Improvements are needed in our abilities to detect cancer at its earliest stages, when the chances for longer-term survival following treatment are the greatest. To address this, NCI is planning to launch the Early Detection Research Network, an interdisciplinary, multi-center effort to discover and coordinate the evaluation of early biological indicators, or biomarkers, of an elevated risk or presence of a cancer. We also expect that tumor diagnosis and classification will be revolutionized in the coming years as emerging knowledge in molecular genetics is applied; tumors will be more accurately diagnosed when the system of tumor classification is changed from a visual to a molecular basis.

Unprecedented opportunities exist to exploit recent advances in biology, chemistry, and technology to accelerate the discovery and testing of new cancer therapies. NCI is currently taking steps to accelerate and improve the system for costly and specialized process involved in drug synthesis, formulation, pharmacology, and toxicology testing necessary to launch initial clinical trials. The meet the complex challenges of cancer, we also need to train new kinds of scientists that cross disciplinary boundaries; increase our training of physicians in the skills of clinical research; and attract increased numbers of minority students and young scientists into all aspects of cancer research.

Breast cancer, environmental risk factors.—Breast cancer advocates charge that genetics does not account for all cancers, citing how rates vary significantly between and within countries. Women in Japan have about 5 times lower breast cancer rates than women in the U.S. And rates in the Northeastern U.S. are substantial higher than in the South. These advocates maintain that NH-I/NCI does not give sufficient attention to environmental risk factors.

Question. Do you agree?

Answer. The National Cancer Institute (NCI) has a long history and an increasing investment in studying environmental causes of cancer. In fiscal year 1997, NCI spent $405 million in this area which has expanded to an estimated $480 million in fiscal year 1999, an 18.5 percent increase. NCI supports a range of studies to identify the mechanism of action of non-infectious agents, conditions, or procedures contributing to the development of cancer. Recently, NCI has recognized the genetic components of cancer, and has a variety of genetic research programs supported at about $90 million. This field is expected to provide a new set of tools for exploring the complex research questions of the environmental contribution to the development of cancer.

It has been very difficult to identify environmental causes of cancer. For example, in the area of common breast cancer, we know that high doses of irradiation are dangerous. But not many women who get breast cancer have a history of high dose irradiation. So, we are also studying radon exposure, x-ray use, and whether subgroups of women have special susceptibility. NCI has many studies looking at chemical, soil components, air and electromagnetism.

We do not have a definite culprit yet. This means we must keep looking for new tools and new forms of analysis that will illuminate the problem in a way we can understand. The reason that it is so challenging to find environmental causes of cancer is that we are all exposed to multiple chemicals and molecules in the water, air, and food. Each incident is a very low exposure level with a cumulative effect over many years. Thus, measurement of the cause and assessment of the later effect are quite complex problems. The development of the field of genetics may offer elegant tools for solving the measurement and assessment issues. The genomic techniques being advanced in cancer research today can give us ways to address the roles of inheritance, exposure to environmental stressors or microorganisms, and the development of cancer. Some genes involved in human cancers have already been identified and mapped to a location on the human genome. Characterizing the activity of these genes in cellular functions is central to determining the roles that they play in the development and progression of cancer. The use of a new technology, cDNA microarrays, may also provide a major breakthrough for environmental cancer as well as benefitting a number of endeavors in business and criminal justice. The microarray technology allows us to trace to genetic differences in the cancer cells. NCI's current efforts with microarrays focus on lymphoma research and have produced a chip called the Lymphochip. Analysis using the lymphochip reveals the fingerprints of genetic pre-disposition and exposure to environmental carcinogens.

Question. How do you involve advocates in planning and priority setting?

Answer. The role of patients and advocates in decision-making at the National Cancer Institute (NCI) has grown in recent years as NCI's mechanisms for obtaining and utilizing their input have expanded.

In 1996, NCI established the Office of Liaison Activities (OLA) to serve as a central point of contact and link to cancer advocacy organizations, and to strengthen NCI's relationships and cooperation with these groups. With the help of that office, the NCI Director, Dr. Richard Klausner, established the Director's Consumer Liaison Group (DCLG), the first all-consumer advocate advisory committee at NCI and the National Institutes of Health (NIH). The DCLG is a landmark initiative that brings together a diverse group of consumer advocates and scientists on a regular basis to address key issues in cancer research.

By virtue of its own work, and by facilitating the broader participation of other consumer advocates in various NCI activities, the DCLG: (1) ensures that cancer patients help to shape the course of NCI's efforts to eradicate this disease; (2) provides a rich source of ideas and viewpoints for NCI; (3) gives the cancer advocacy community an opportunity to provide input in the planning of NCI programs and future directions; (4) is a channel for consumers to voice their opinions and concerns; and (5) provides NCI with advice and feedback from the consumer community on a broad array of issues.

NCI's OLA also facilitates and tracks other NCI activities involving cancer consumer advocates, including the following:

Participation on a variety of NCI advisory committees, including the National Cancer Advisory Board (NCAB), and review groups to help NCI determine the current state of research in the most prevalent cancers affecting men and women, such as prostate and breast cancers.

Participation on Planning Committees to identify new extraordinary opportunities for research to be addressed in the future.

Participation in workshops in 1996 and 1997 to shape the research priorities of the Office of Cancer Survivorship (OCS), which was established in 1996.

Participation in a workshop in the fall of 1998 to identify gaps in reproductive research for cancer survivors sponsored by NCI's Cancer Therapy Evaluation Program.

Serving on NCI peer review groups evaluating special competitions for contracts and grants. In 1998, for example, consumers served as full voting members of a peer review panel evaluating grant applications received in response to NCI's request to develop research projects in cancer survivorship which were awarded in the fall of 1998. This year, NCI expanded its use of consumers in review panels for grants to cancer centers and for grants supporting Specialized Programs of Research Excellence on specific cancers. They also participate in the review of grant and contract applications for clinical studies and population-based (epidemiological) research.

Recognizing the importance of receiving input from all areas of the cancer research enterprise, NCI continues to reach out to various constituency groups through a number of mechanisms to seek guidance on promising new avenues of research. This approach is most recently exemplified through NCI's Progress Review Groups (PRGs) in Breast and Prostate Cancer.

The PRGs were first convened in 1997. They were charged with developing a national plan consisting of a description of ongoing scientific activities and investiga-

tions relevant to breast and prostate cancer and listing, in priority order, the scientific opportunities that should be pursued. Each Review Group was composed of prominent members of the scientific, medical, industrial, and advocacy communities in order to represent the full spectrum of expertise needed to develop comprehensive recommendations on the cancer research agenda.

In January 1999, the NCI held meetings with each PRG to discuss this response and found that the PRG members are pleased with both the Institute's overall response and the Institute's response to individual recommendations. NCI and the PRG members plan to meet in a year to discuss the progress of the implementation and to address any necessary mid-course corrections.

Overall, both the NCI and the participants were pleased with the outcome of the PRGs, and we consider the approach to be a notable success. The PRG mechanism was particularly successful in providing a foundation on which future research directions can rest. However, the process was long, time-consuming, and costly, and NCI staff and PRG members found the PRG process itself to be too intensive to do routinely for all cancers. That said, NCI learned a great deal about what works and, just as importantly, what does not work in conducting a review of this magnitude, and it is quite possible that a streamlined version of the PRG process will be employed in the future for other cancers.

Question. What is the proper balance, between genetic vs. environmental risk factors?

Answer. This question has a complex answer that has been much discussed at NIH, in Congress, and among our many advisory groups in the context of directing funds to specific diseases and in the setting of basic research priorities. A particularly important issue in balancing genetic and environmental research priorities is the contribution basic research makes to the eventual solution of medical problems. Basic research enables the new insights into the disease that may lead to a new cure or treatment. About half the NCI budget is devoted to basic research, the core of our national cancer research program. These basic research projects may appear initially to be unrelated to any specific disease, but often contribute substantially to the long chain of discoveries leading to improved health.

There is no "right" amount of money, percentage of the budget, or number of projects for genetic vs. environmental risk factors. NCI responds to the needs of breast cancer researchers and public health needs, by weighing multiple factors including the incidence, severity, and cost breast cancer as well as scientific merit assigned by peer review, the likelihood of an important result, the necessity to ensure diversity in the portfolio.

We recognize a desperate need to find accurate markers of breast cancer that are sensitive and predictive for the development of this dreadful disease so that it can be caught early. NCI has launched a major program, the Cancer Genome Anatomy Project (CGAP), now funded for $8 million, which has the potential to provide this information by discovering new leads on the genetic basis of breast cancer.

The overall goal of CGAP is to achieve the comprehensive molecular characterization of normal, precancerous, and malignant cells. Toward that end, NCI has implemented several CGAP components to provide an information and technology infrastructure for the biomedical researchers. One of these components, the human tumor gene index (TGI), was fully implemented in May 1997 with the initial goal of identifying genes expressed during development of tumors in five major cancer sites—markers for breast, colon, lung, ovary, and prostate. For breast cancer, the TGI has produced more than 15,000 DNA sequences from 11 cDNA libraries derived from human breast tissue and tumors, resulting in the discovery of over 350 human genes never seen before in any human tissue. The next step is to assess the potential value of these newly discovered genes in molecular diagnostics and to develop sensitive and specific tests for the early detection of cancer. We will probably find that the majority of these genes are expressed elsewhere in the body, or as a result of a process other than development of breast cancer. However, we are excited about this new tool's potential to help us develop a test for early detection of cancer.

NCI's new initiative "The Director's Challenge: Toward a Molecular Classification of Tumors" will provide $50 million over five years to exploit emerging comprehensive molecular analysis technologies to change the way tumors are classified from their microscopic appearance to their molecular characteristics. In this initiative, information and reagents developed through the CGAP program will be utilized to develop molecular profiles of breast and other tumors and correlate gene expression patterns with a variety of clinical parameters. This research, carried out by multidisciplinary groups, will focus on the application of modern molecular technologies to the analysis of specimens from breast and other tumors, including comparisons between normal, precancerous and malignant tissues. The primary goal of this initiative is to define profiles of molecular alterations in tumors that can be used to

define specific subsets of patients, for example node-negative breast cancer patients, in which the biological heterogeneity is high. Such profiles will lay the groundwork for future studies to validate the clinical utility of molecular-based classification schemes. A tangible goal of this initiative is the generation and dissemination to the scientific community of the extensive, information-rich data sets expected to result from these projects.

To promote progress in early detection of breast and other tumors, NCI is establishing a multi-institutional consortium to develop, evaluate and validate biomarkers for cancer detection and risk assessment. This consortium will allow us to take the potential markers discovered through CGAP and test them in people with or at risk for cancer. This initiative, the Early Detection Research Network, is funded for $61 million over five years and will link centers of expertise in tumor biology, diagnostics technologies, and clinical trials methodology in academia and industry to develop high-throughput assays suitable for clinical testing. With a focus on breast cancer, these assays will involve advanced analytic tools that permit a detailed examination of the molecular basis of carcinogenesis, provide the ability to identify the molecular and cellular signatures of cancer, and to explore gene-environment interactions relevant to early detection. To expedite the discovery and development of more sensitive and specific markers for early and aggressive disease, NCI will also establish links between activities of the Network and programs in academia and industry that are developing libraries of all known secreted proteins in mammalian cells.

Feinstein clinical trials database.—The FDA Modernization Act of November 1997 requires HHS to establish a database of all clinical trials so that patients and physicians can find out what research is being conducted on various diseases. This bill, now law, also required creation of a toll-free telephone number.

Question. I know there have been some planning meetings. What exactly is the status? When will it be operational? When can I call that toll-free number and find out about a trial?

Answer. The FDA Modernization Act required establishment of a database of clinical trials and also a toll-free telephone number for disseminating the database information. Thus, creation of the database, including a search engine, is a first step, with the toll-free telephone a later step. The database information is well underway, with seven separate databases now available on NIH's Home Page at http://www.nih.gov/health/trials/index.htm. These seven are: CancerTrials; AIDS clinical trials; trials conducted at the NIH Clinical Center in Bethesda, Maryland; eye disease trials; rare disease trials; heart, lung and blood disease trials; and trials for infectious, immunologic, and allergic diseases. A central search engine is being developed by the National Library of Medicine that can automatically search all of the databases and at the same time, other NIH institutes are building their databases of clinical trials that will eventually be linked to the central search engine. Our plan is to have all the NIH clinical trials on the Internet by the end of 1999. We will also be establishing a clinical trials database to which other Federal agencies and the private sector will submit information (as required by the law), with a goal of beginning this database in 2000. The toll-free telephone system will depend upon having these linked databases established and operational. We are already starting to plan for the toll-free telephone line, however. A Request for Proposals (RFP) is being developed now for a two-year study to determine how best to set up the toll-free telephone line, aimed at learning how to do this in the most effective, cost-efficient manner and also to pilot some options for the public service. In the meantime, NIH does have some toll free telephone lines that people can use to learn about clinical trials (in addition to getting other health-related information). The most well known is the Cancer Information Service, 1–800–4–CANCER. The other NIH toll-free telephone numbers can be found on the NIH Home Page at http://www.nih.gov/news/infoline.htm.

Medicare cuts.—The administration has proposed substantial cuts in Medicare funding to hospitals. These are in addition to cuts enacted under the Balanced Budget Act of 1997. California hospitals will have Medicare payments cut by over $5.2 billion with the majority of cuts taking place after the year 2000. User fees on hospitals and doctors totaling $1.516 billion for Medicare services are also proposed.

California hospitals had negative operating margins in 1997–1998 according to the California office of Statewide Health Planning and Development. HHS officials have quoted 16 percent hospital margins, but note that this figure represents aggregate, national data and said their figures could not be broken down by region.

Question. Has the Department measured how prior and proposed cuts affect particular regions or states? In California for example, the average length of hospital stay is one day shorter than the national average because of the heavy prevalence of managed care.

Answer. We have thoroughly assessed the potential impacts of a zero update to the hospital inpatient prospective payment amounts for fiscal year 2000, and believe that hospitals are well able to absorb those impacts. Hospitals' Medicare costs per case declined in real terms from 1994 through 1997, while payments under the prospective payment system increased each of those years. As a result, in 1997, hospitals' Medicare operating margins were 16.1 percent higher-than the 1995 margins which prompted Congress to enact a zero update to the prospective payment amounts under the Balanced Budget Act.

In California, hospitals' Medicare operating margins have been among the highest in the country recently. In 1997, for example, Medicare payments exceeded hospitals' costs by 23.6 percent. California hospitals have successfully reduced average lengths of stay well below the national average. Because shorter lengths of stay generally mean lower costs, this is a big factor in their above-average operating margins.

Question. Has the Department considered how cuts in Medicare will affect the ability to provide services to those presently served by Medicare and those for who?

Answer. As noted above, the latest available data show that Medicare is paying well in excess of hospitals' costs. Thus, we do not believe that holding Medicare prospective payments at their fiscal year 1999 level in fiscal year 2000 will adversely affect hospitals' ability to provide services to Medicare beneficiaries. To the contrary, we believe that a zero update represents a prudent and appropriate course designed to allow the Hospital Insurance Trust Fund to benefit from hospitals' efficiency improvements over the last several years.

Health professions shortages.—The budget proposes complete elimination (0 funding) of the Primary Care Medicine and Dentistry Program which provides practitioners who are trained to work in underserved areas—400 nationwide in the fiscal year 1999 budget. The program received $80 million in fiscal year 1999. A total reduction in all health professions programs of $50 M. is requested. The National Health Service Corp which provides incentives for health practitioners to practice in underserved areas was able to only fund 60 percent of the requests for providers in underserved areas in 1999 and the Department has proposed no additional funding for these unmet needs.

Question. California has many underserved urban and rural areas, 183 in primary care, by one count. How can you expand the availability of health services by reducing training of qualified health professionals?

Answer. The Department recognizes that the training of primary care physicians and physician assistants is a critical need. However, there are also severe national needs in other areas. For these particular programs, the Department believes that other forces such as market demand, the Medicare program, the states, and educational institutions will provide resources for training of these health care providers.

Tobacco settlement funds, federal share.—States settled with tobacco companies in the fall of 1998 for $206 billion. California will get approximately $25 billion. Current Federal law requires recoupment of the Federal share of Medicaid funds, and the administration had received some funds from earlier settlements by individual states but has suspended such efforts for the present.

White House domestic policy adviser Bruce Reed has said that the Administration will oppose legislation that would permit the states to keep these settlement funds outright. He said that the administration will work with the states and Congress to resolve the Federal claim in exchange for a commitment to use the Federal portion on shared priorities, citing youth smoking, improved public health, and assistance to children. The fiscal year 2000 budget includes recoupment of $9.1 billion in recoupment through 2004.

Question. What are the Department's plans to go ahead with the recoupment?

Answer. Current Medicaid law requires HCFA to recoup the Federal share (on average 57 percent) of all State third-party liability collections, including the recent State tobacco settlements. Since US taxpayers paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes that the Federal government will follow the law and claim its share of the proceeds.

However, the Administration will work with the States and the Congress to enact tobacco legislation that, among other things, resolves these Federal claims in exchange for a commitment by the States that the Federal share of the settlement's proceeds will be spent on shared national and State priorities: to reduce youth smoking, protect tobacco farmers, improve public health, and assist children.

It is for this reason that the Administration has delayed action on claiming the Federal share of the State tobacco settlements until fiscal year 2001 so that we can work with the States and Congress over the next year on mutually agreeable legislation.

Question. The argument has been advanced that the settlement resolves other issues besides Medicaid, including antitrust issues. What plans does the Department have to discuss with the states how the Federal claim is to be determined?

Answer. The Administration believes that Medicaid costs were the basis for the States' recovery. Regardless of each State's litigation against the tobacco companies, all of the States specifically agreed to include present and future Medicaid claims in the settlement. Current Medicaid law requires HCFA to recoup the Federal share—on average 57 percent—of all State third party liability collections, including the recent State tobacco settlements. Since the Federal government paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes the Federal government will claim its share of the proceeds. However, the Administration proposes to work with the States and with Congress to enact tobacco legislation that, among other things, resolves these Federal claims in exchange for a commitment by the States to use tobacco money to support shared State and national priorities which reduce youth smoking, promote public health, help children, and assist tobacco farmers and their communities.

Question. What role will the Department take in the Administration's plans to work with states about use of tobacco settlement funds? What services would the Department target and what flexibility would go to the states in the use of the funds? How can we assure that they will be used for tobacco-related health purposes?

Answer. The President has made clear his desire to work with Congress on legislation that would waive of the Federal share of the multistate tobacco settlement if the States agree to use these funds for shared State/Federal priorities to reduce youth smoking, protect tobacco farmers, assist children, and promote public health. The Department has been working closely with other parts of the Administration on this issue.

Bioterrorism initiative.—You have proposed $230 million to counter bioterrorism threats, for vaccine research and development, public health surveillance, and Local Metropolitan Medical Response Systems. The Department of Defense and Department of Justice would also receive funds for training.

Over $300 million was appropriated nationwide in fiscal year 1999. In California, the bulk of funds to date for emergency response has been directed to the largest metropolitan areas. There have been a rash of threats involving anthrax in recent months, over 20 alone in Los Angeles. Threats also have been directed at Congress, and Federal agencies, very recently.

Question. How is the Department coordinating its initiatives with other Federal agencies and with state and Local agencies?

Answer. HHS works closely with several other agencies to ensure that plans for managing the medical consequences of terrorist acts are well integrated with our emergency response systems. We work especially closely with the relevant components of the Departments of Justice (DOJ), Defense (DOD), and Veterans Affairs (VA), and with the Federal Emergency Management Agency (FEMA). Some examples of this cooperation include: providing medical technical assistance to the Federal Bureau of Investigation (FBI) when confronted with situations or threats potentially involving anthrax; supporting emergency medical care and assistance to US citizens overseas through specific requests from the State Department; participating in activities of DOJ's National Domestic Preparedness Office; and involving other agencies in an interagency process to review contracts to related to some of HHS's bioterrorism initiatives. HHS is also represented on the Weapons of Mass Destruction Preparedness Working Group.3

Question. How has the Department prioritized resources to target for funds? Should metropolitan areas be the first priority?

Answer. Departmental resources have been targeted to five primary areas: (1) deterrence of biological terrorism; (2) surveillance for unusual outbreaks of illness; (3) medical and public health response; (4) development of a national pharmaceutical stockpile; and, (5) research and development.

States and local communities are the primary priorities for funding. For example, the Centers for Disease Control and Prevention (CDC) is working to upgrade public health capability to counter bioterrorism through State and local health departments, and within CDC. The medical and public health response initiative works extensively through local governments to develop Metropolitan Medical Response Systems (MMRS). The MMRS development program, begun in fiscal year 1995, targets the largest metropolitan areas in the United States and seeks to improve local capability and capacity to respond to a terrorist event. There are 27 cities currently engaged in the MMRS development process. HHS intends to begin development in 20 additional metropolitan areas during fiscal year 1999, and to work with the first

27 cities to enhance the biological preparedness component of the systems. For fiscal year 2000, we are requesting funds to start systems in 25 more cities.

Question. In addition to the first responders such as fire, police, and EMS, other aspects of the health care infrastructure will be involved, including hospitals and emergency departments. How is the Department planning to include assistance to such entities in its initiatives?

Answer. The MMRS development program contractually requires communities to develop integrated systems plans for the public health and medical response to incidents involving weapons of mass destruction. This planning process must include not only the traditional emergency response agencies (e.g., police, fire, EMS, HAZMAT), but also hospitals and other critical public health agencies.

In an effort to improve the local capability and capacity to respond to the consequences of biological terrorism, the Department is planning to revisit the 27 original MMRS cities to develop plans for the public health and medical consequences of biological terrorism and naturally occurring pandemics.

Closely related to this effort, CDC has been tasked to strengthen the nation's public health infrastructure. CDC will award cooperative agreements to State health departments, to help upgrade State and local surveillance capabilities. These agreements will focus on State and local preparedness, enhancement of detection, epidemiological and laboratory capabilities, and the Health Alert Network.

Question. Does the Department have any special plans to address the issue of threats and hoaxes in its initiatives?

Answer. The response to threats and hoaxes regarding any form of terrorism, including bioterrorism, is in the crisis management domain of the FBI. The FBI collaborates closely with HHS in analyzing threats involving the terrorist use of weapons of mass destruction, to determine their credibility and the response required. Many recent threats have been determined to be hoaxes. Since there is always an element of anxiety with regard to any terrorist threat, particularly biological, HHS has coordinated with the FBI to develop procedural advisories directed toward the FBI field elements who investigate such threats.

Y2K planning.—An August 1998 GAO report said that HCFA's systems supporting Medicare are not Year 2000 compatible, that HCFA was "far behind" in repairing and testing systems. HHS has said they planned to have all HHS systems "millennium compliant" by December 1998.

Question. Can we assure Medicare beneficiaries that they will see no disruption in payments and services in January 2000?

Answer. HCFA has made significant progress in readying its computer systems for the Year 2000, and will continue its aggressive work to ensure that health care providers will be paid for the care they give to Medicare beneficiaries. Although HCFA can assure that Medicare's claims processing and payment systems will function, continuity of care will depend on the providers' ability to continue to operate their offices and generate claims that can be processed by those systems. Doctors, hospitals, and other providers are responsible for ensuring that their systems are Year 2000 compliant. Because of its concern for continuity of care to Medicare beneficiaries, HCFA has embarked upon an unprecedented outreach effort to help its partners meet their responsibility, as we are meeting ours.

Lead screening.—A GAO report has documented that very few children on Medicaid are screened for lead. California has more than 200,000 children with elevated levels of lead in their blood. Lead toxicity can harm cognitive development and at higher levels can case seizures, coma and death. Federal law requires Medicaid programs to ensure that children receive lead screening.

Question. What are you doing about this? Are you enforcing this requirement?

Answer. The Health Care Financing Administration is establishing a Lead Screening Workgroup to implement and follow-up on the progress toward fulfilling the recommendations of the GAO report. Members of the workgroup include the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), Agency for Health Care Policy and Research (AHCPR), and the Administration for Children and Families (ACF). We are in the process of developing a comprehensive departmental action plan for implementing the recommendations.

In addition, HCFA has several action items which we will be addressing in the next few months. We are releasing a letter to all State Medicaid Directors reiterating our mandatory policy on lead screening and the importance of lead screening for Medicaid eligible children. We also intend to clarify our policy on several reimbursement issues which GAO raised.

We are also in the process of revising the HCFA–416, the annual reporting form for Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services, to in-

clude a line item which will require states to report how many children received screening blood lead tests.

Children's health insurance program (CHIP).—The Children's Health Insurance Program (CHIP) is a Federal program enacted in 1997 to increase availability of health insurance for children and has been implemented in California as the Healthy Families Program. For children who are not eligible for Medi-Cal but whose families are poor at less than 201 percent of poverty level, insurance is available at cost of $4–$9 per child per month (up to maximum of $27). California has received $859 million each year for fiscal year 1997, fiscal year 1998, and fiscal year 1999 for a total of $2.577 billion for the three years in Federal funds. Enrollment has been slow in California and other states. As of mid-February 1999, 71,958 California children were enrolled out of 250,000—385,000 who are eligible.

Impediments to enrollment in California include a complicated application and fear by immigrant parents that signing up their children could affect U.S. residency and invite retaliation by the INS.

Question. When will the new funding for outreach be available to states?

Answer. The Administration's fiscal year 2000 budget includes two outreach proposals. Neither proposal makes new funds available, but increases state flexibility in using existing funding.

These proposals are:

Expanding the use of outreach funding authorized under welfare reform

This proposal would permit States to expand the use of a special $500 million Medicaid fund, enacted in the 1996 welfare law, now aimed at outreach for children losing welfare, to fund outreach to other children eligible for Medicaid, and to new children eligible for CHIP. In addition, the proposal would remove the sunset on the fund, currently scheduled for fiscal year 2000. This proposal is expected to increase Medicaid spending by $345 million over the next five years, including both administrative expenses and benefits.

Establishing a separate 3 percent CHIP outreach cap

Under this proposal, spending for CHIP outreach would be removed from the 10 percent administrative cap and a separate 3 percent outreach cap would be established. States would be permitted to use an additional 3 percent of their total benefits expenditures for outreach. This proposal will allow States to increase spending on outreach, which will lead to accelerated outreach and benefits spending under the allotments. We expect that the overall CHIP spending baseline on outreach and benefits will increase $875 million from fiscal year 2001–2004 as States identify more CHIP-eligible kids.

Question. What efforts is the Department making to accelerate enrollment in California, especially in clarifying eligibility criteria with the Immigration and Naturalization Service?

Answer. The CHIP law provides states with significant flexibility in designing their CHIP programs, including outreach. The Department continues to work with California and supports its efforts to increase enrollment in Healthy Families. A representative from HCFA attends California's monthly Board meetings of the Managed Risk Medical Insurance Board (MRMIB), and participates in the State's monthly joint meetings of the Healthy Families Advisory Committee and the Education and Outreach Committee. In addition, HCFA has participated in the public meetings of the workgroup that advises the State in its effort to revise the Healthy Families application. The first meeting was a public meeting attended by advocates, counties, providers, and other stakeholders; and the latter two meetings involved a wide range of advocates and counties. We have provided regular feedback to the State on its application revision efforts.

HCFA also holds regular discussions with both the California Department of Health Services (DHS), which oversees the State's outreach activities for Healthy Families, and with MRMIB, the agency that administers Healthy Families.

All of the State's outreach efforts have a focus on the Hispanic population, which comprises 75 percent of the Healthy Families Program's target population (Hispanics comprise 60 percent of all uninsured children who are eligible for Medi-Cal). HCFA continues to work with the State to improve outreach to Hispanics by getting California's revised application out as soon as feasible, providing direct funding for outreach to community-based organizations, widely distributing information about the Immigration and Naturalization Service (INS) policy to the Hispanic community, and improving outreach to those Hispanics whose eligibility is clear. The Department supports California's efforts to solicit further policy clarification from the INS and is working closely with the White House and INS to accomplish this goal.

QUESTIONS SUBMITTED BY SENATOR ROBERT C. BYRD

THE MEDICARE SUBVENTION DEMONSTRATION

The Department of Health and Human Services (HHS), in conjunction with the Department of Veterans Affairs (VA), is conducting a demonstration project to provide important information on treating dual eligible, Medicare-VA beneficiaries. It is important to ensure that these beneficiaries receive quality health care.

Question. What is the status of this demonstration and when will results be available?

Answer. There currently is no demonstration project between the Department of Health and Human Services and the Department of Veterans Affairs. Because sections 1814(c) and 1835(d) of the Social Security Amendments prohibit Medicare payments to any Federal provider of services (except Indian Health Service), we cannot enter into a demonstration to pay for care at VA facilities for dual-eligible beneficiaries without statutory authorization.

A memorandum of agreement was signed by the two Departments in September 1997 which provides the framework for a demonstration, pending authorization. We are providing technical assistance to Senate staff on legislation which would both protect the Medicare trust funds, and test the impact of a subvention demonstration on access to care for beneficiaries, quality of care, and cost of the program to the two Departments and beneficiaries.

We received authorization in section 4015 of the Balanced Budget Act of 1997 to conduct a subvention demonstration with the Department of Defense at six sites. This demonstration is now operational and is being evaluated by an independent evaluator, as well as the General Accounting Office. Because the last two sites began delivering services in January 1999, it will be about another year before we have preliminary results on the program.

Y2K AND RURAL HEALTH CARE

In many industries, the larger players are better situated in terms of addressing the Year 2000 computer problem (Y2K). In the health care industry, I am concerned that smaller health care providers may not be as far along in ensuring that their systems are ready for the new millennium, especially in rural areas where these providers are so important to the people they serve.

Question. Is HHS working with rural hospitals to help them become Y2K compliant?

Answer. HCFA is working on outreach to all Medicare providers to alert them to the need to resolve their Y2K problems and has made available a set of self-help materials to guide providers toward Y2K readiness. HCFA meets with a number of major medical associations regularly, including the National Rural Health Association. Also, HCFA is working to increase our efforts in the rural communities, because such communities may not have the resources available to take ready advantage of our Internet materials.

In an unprecedented step in January 1999, HCFA sent letters to over 1.3 million Medicare providers to provide important information regarding Y2K, and has trained speakers in all HCFA regional offices so they may present Y2K information to local and state provider groups, especially in rural areas.

Question. What outreach efforts have been made, and where can rural health providers turn, for Y2K information?

Answer. As mentioned previously, HCFA sent letters to all Medicare providers, has trained speakers to do Y2K outreach to State and local provider groups, and meets regularly with the National Rural Health Association (NRHA) and other rural health groups.

In addition, HCFA made a presentation at NRHA's recent annual Rural Health Policy Institute, attended by over 275 individuals from over 41 States to convey the Y2K message. Representatives from HCFA have attended rural health forums in Spearfish, South Dakota, and Lansing, Michigan, and plan to attend sessions in many other areas of the country to reach rural providers. Also, in a letter to every Member of Congress, HCFA offered to go to their districts to present the Y2K message to their provider constituencies.

HCFA will intensify its efforts to reach rural providers by:

Collaborating with additional rural provider associations;

Talking with software vendors and billing services with a heavy rural provider clientele to see what efforts those organizations are doing to prepare their customers for Y2K;

Ensuring that rural provider group meetings are attended by HCFA speakers to convey the Y2K message; and

Encouraging rural associations to strengthen their own outreach efforts to their members.

Further, providers can contact their Medicare contractor for free Y2K-ready software.

DIETARY GUIDELINES

It is my understanding that HHS is working in conjunction with the U.S. Department of Agriculture to update the Dietary Guidelines which provide important nutrition and health guidance to Americans. The fifth edition of the Guidelines is to be published in the year 2000. The section which addresses alcohol will likely be examined in this process. In recent years, research has been reported about alcohol's health benefits while other studies have shown health risks associated with alcohol use. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is currently conducting research on moderate drinking.

Question. Given the ongoing research at the NIAAA about the health benefits and health risks of moderate drinking, can we be sure that accurate and complete information will be available to provide to the American public?

Answer. NIAAA's data on health benefits and health risks of moderate alcohol consumption are available to the U.S. Department of Agriculture's Dietary Guidelines Advisory Committee. Numerous studies on this topic have been completed, and several more are underway. At this time, however, the data are incomplete. While research indicates that moderate alcohol consumption provides certain benefits, not enough is known about its risks. Another concern is that appropriate dosages for health benefits are not firmly established. In addition, the dichotomous view that alcohol is either only beneficial or only harmful is too simplistic. An alcohol dose that is beneficial to the heart, for example, may be implicated in other diseases.

Many areas of risk associated with moderate alcohol use must be further delineated. For example, some studies indicate that moderate drinking is a risk factor for hemorrhagic stroke and breast cancer. Experimental studies in animals suggest that alcohol is a cocarcinogen or a tumor promoter. The mechanisms by which maternal alcohol intake damages the developing fetus remain unclear, as do the dosages of alcohol that trigger those mechanisms.

While most people who drink do so moderately and without problem, some people should not drink at all, because they are genetically or environmentally vulnerable to alcoholism and its consequences. Also unknown at this time is the effect that a generalized public-health prescription for alcohol intake would have on progression to heavy drinking and alcoholism among this vulnerable group, as well as those in whom such risk factors are absent. It is worth noting that alcoholism is a very prevalent disease, from which 14 million adult Americans suffer.

Currently, NIAAA devotes $3 million to the study of health benefits and health risks of moderate alcohol consumption.

UNDERAGE DRINKING

I wrote to you in January to urge you to update the reports issued in 1991 by the HHS Inspector General regarding youth and alcohol. The information in these reports has been helpful in understanding the scope and nature of our nation's underage drinking problem. However, the data is outdated.

Question. Do you anticipate directing the HHS Inspector General to update these reports, and when might this be accomplished?

Answer. Your request was forwarded to the Office of Inspector General and the Inspector General agrees that it is important and timely to update this work. The OIG is currently developing a study proposal for the fiscal year 2000 work plan and expects that this study would be complete by the end of fiscal year 2000.

APPALACHIAN LABORATORY FOR OCCUPATIONAL SAFETY AND HEALTH

Question. What is the number of Full-Time Equivalents (FTE) for the Division of Safety Research and the Division of Respiratory Disease Studies at this facility in fiscal year 1999, and the number projected for fiscal year 2000?

Answer. CDC expects the Division of Safety Research to use 107 FTE in fiscal year 1999 and in fiscal year 2000. CDC expects the Division of Respiratory Disease Studies to use 135 FTE in fiscal year 1999, and in fiscal year 2000.

Question. Please provide the funding level for the above-mentioned Divisions in fiscal year 1999, and the projected level for fiscal year 2000.

Answer. For the Division of Safety Research, CDC's budget includes $11.8 million in fiscal year 1999 and $12.1 million in fiscal year 2000. CDC's budget includes $12.0 million for the Division of Respiratory Disease Studies in fiscal year 1999, and $12.3 million in fiscal year 2000.

THE NEW OCCUPATIONAL SAFETY AND HEALTH LABORATORY

Question. How many FTEs are at this facility in fiscal year 1999, and what is the projected number of FTEs at this facility for fiscal year 2000?

Answer. In both fiscal year 1999 and 2000, CDC's estimate for the number of FTE for the facility is 303.

Question. Please furnish the funding level required for staffing and research for fiscal year 2000 at this facility.

Answer. The funding level in fiscal year 1999 is $36.0 million. The proposed fiscal year 2000 funding level is $38.5 million, including both intramural and extramural research.

QUESTIONS SUBMITTED BY SENATOR SLADE GORTON

The Administration is proposing another Medicare reduction beyond those included in BBA 97 of nearly $9 billion over 5 years, including a market basket freeze. The market basket freeze is being proposed at a time when even MedPAC is recommending a 0.7 percent update.

Question. What is the justification for freezing hospital rates? Do you anticipate that it will impact on patient care?

Answer. The results of our analysis are consistent with those of MedPAC. That is, through 1997, hospitals' Medicare costs per case continued to decline in real terms. This marked the fourth consecutive year of declining costs per case. Medicare PPS payments continued to rise throughout this period until the one-year freeze enacted by the BBA for fiscal year 1998. Based on the high Medicare operating margins during fiscal year 1996 and fiscal year 1997, we are confident that another one-year freeze in updates to hospitals' PPS payments is warranted, given the fact that hospitals' costs per case would have to have increased by nearly 6 percent per year since fiscal year 1997 for Medicare payments and costs to have reached the break-even point.

As the inpatient hospital prospective payments compensate in excess of costs, on average, and as the system makes special provision for groups of institutions facing more difficult financial situations (such as smaller rural hospitals), we expect that Medicare rates will continue to support quality care for our enrollees.

According to MedPAC, hospitals now paid 82 cents on the dollar for outpatient services. Once the BBA goes into full effect, it will go down to 78 cents. Rural hospitals get 73 cents on the dollar, while cancer hospitals will get 58 cents on the dollar.

Question. If a hospital has a high volume of Medicare patients, such as some of the ones in my state, how would you expect it to survive if Medicare continues to pay less than the cost of actually providing patient care, particularly outpatient care?

Answer. In the beginning of the Medicare program, we paid hospitals for furnishing outpatient services to Medicare beneficiaries based on the costs hospitals incurred to provide those services. Medicare legislation in the late 1980s made some changes to move away from recognizing full costs. For example, section 1861(v)(2)(S)(ii) of the Social Security Act (the Act) requires that for calculating outpatient payments for hospitals (other than sole community and critical access hospitals), we recognize only 90 percent of the costs hospitals incur for capital costs and 94.2 percent of the costs they incur for operating costs. In addition, Congress attempted to "level the playing field" across ambulatory sites in sections 1833(I)(3)(A) and 1833(n)(1)(A) of the Act by requiring that we pay for certain hospital outpatient surgical, radiology and other diagnostic procedures based on the lower of (1) the hospital's costs or (2) a blended amount based, in part, on their costs and, in part, on the amount that Medicare pays under fee schedules in other ambulatory settings, i.e., ambulatory surgical centers and physician offices. As a result of changes such as these, we currently pay hospitals less than their full costs.

Section 4523 of the Balanced Budget Act establishes a prospective payment system (PPS) for hospital outpatient services. This section requires payments under the new system to be based on an amount which reflects what the Medicare program would have paid for hospital outpatient services in 1999 under the current payment system plus what beneficiaries would have paid in 1999 as coinsurance under the new prospective payment system. To the extent that PPS payments are based on current Medicare program payments, they will incorporate the current level of cost reductions that hospitals experience now. Under the PPS, beneficiaries will pay less than they currently pay. Therefore, to the extent that PPS payments are also based on what beneficiaries will pay under the new system, hospitals will experience additional reductions in payments.

In the September 8, 1998, proposed rule for the hospital outpatient PPS, we estimated that, in the aggregate, hospitals will experience a decrease in payments of 3.8 percent as compared to current payments they receive for hospital outpatient services. Our proposed rule estimates that rural hospitals and cancer centers will experience even greater decreases. However, in the proposed rule, we state that HCFA plans to do additional analyses to examine the way these hospitals coded their bills in order to try to determine whether their coding practices can explain the negative impacts. We also state that, although we have not provided for any payment adjustments in the proposed rule, following our analyses we will consider whether an adjustment is needed to moderate the impact on these types of hospitals.

Many of the hospitals in my state are rural and they are just now beginning to feel the adverse impact of the BBA on their ability to deliver patient care services. The BBA has produced a number of unintended consequences that I suspect will be exacerbated by an additional reduction in Medicare spending. Many of these hospitals also operate a skilled nursing facility and a home health agency in order to serve their communities, and are being squeezed in all these areas.

Question. How do you intend to address some of these problems?

Answer. When Congress passed the Balanced Budget Act of 1997, it included several provisions designed to aid certain rural hospitals. Payments to certain Medicare-dependent small rural hospitals were increased. Many hospitals that had lost their status as Rural Referral Centers were reinstated. The Medicare Rural Hospital Flexibility Program, providing reasonable cost reimbursement to hospitals designated as Critical Access Hospitals, was established. We have done all that we can to ensure these provisions specifically targeting rural hospitals have been expeditiously implemented. Furthermore, Medicare has had a number of provisions in place for some time that are designed to give preferential payment treatment to rural hospitals. We are confident that these provisions will continue to ensure that rural Medicare beneficiaries will have access to quality hospital care into the future.

HCFA estimates an overall decrease in claims volume, the first time since the inception of the program more than thirty years ago, of over 1 percent. You state that this decrease is attributable to beneficiaries taking advantage of the Medicare + Choice options offered under BBA 97.

Question. Please explain how you concluded there would be a decrease in the number of Medicare beneficiary claims when available information indicates that there may not be a large, if any, increase in Medicare + Choice enrollees.

Answer. When HCFA began formulating the fiscal year 2000 President's budget request in April 1998, we had actual claims data for fiscal year 1997 and the first few months of fiscal year 1998. Workload analysis at that time showed that claims volumes were still increasing, but not by as much as we had previously expected. The volume we projected for fiscal year 2000—925 million claims—was a slight decrease relative to the fiscal year 1999 President's budget, but it reflected what we felt was a statistical trend toward smaller increases in the fee-for-service workload.

This trend has continued. We currently project that the fiscal year 1999 claims workload will be higher than fiscal year 1998. Consistent with this, our fiscal year 2000 estimate represents a moderate increase over the volume currently projected for fiscal year 1999. However, both the fiscal year 2000 estimate and the fiscal year 1999 current projection are lower than they were a year ago in the fiscal year 1999 President's budget.

Question. You allude in your budget that as HCFA moves down the road of fundamental reform, the Administration will review legislative proposals to increase the stability of HCFA's funding. Please explain what kind of legislative proposals you are considering.

Answer. In recent years, HCFA's Program Management budget has remained relatively flat, while our legislative and operational challenges have continued to increase. Congress began to address this last year when HCFA received more than an 8 percent increase in program level to fund important activities such as BBA and HIPAA implementation and Y2K remediation. HCFA's fiscal year 2000 budget request provides for a 6 percent increase over fiscal year 1999, which is necessary to meet HCFA's expanding programmatic responsibilities, as well as priority base activities. We thank Congress for providing the fiscal year 1999 increase, and we look forward to working with Congress to ensure that HCFA receives its full budget request for fiscal year 2000.

HCFA is also engaged in a management reform initiative, highlighted in the President's budget, that will help us make the most efficient use of our resources and adapt to the changing health care market.

The Administration will work with the Committee to explore funding options. We note that the fiscal year 2000 budget includes user fee proposals which would de-

crease the funding required by annual appropriations, and we will be pleased to share additional funding proposals once they are more fully developed.

QUESTIONS SUBMITTED BY SENATOR KAY BAILEY HUTCHISON

As you may be aware, states that sued the tobacco industry asserted in their complaints a wide variety of causes of action, including everything from state consumer protection statutes to racketeering, to antitrust violations. And while many states did assert direct health care costs, including Medicaid costs, in their lawsuits, others did not, and still others had their Medicaid claims thrown-out by the courts. In any event, virtually none of the settlements, except Florida, even mentions Medicaid.

Question. In light of this, how can you justify the Administration's budget submission, which assumes that every single dollar recovered by every state as part of their tobacco suit 50 settlements is directly attributable to Medicaid costs?

Answer. The Administration believes that Medicaid costs were the basis for the States recovery. Regardless of each State's litigation against the tobacco companies, all of the States specifically agreed to include present and future Medicaid claims in the settlement. The Department of Justice has determined that by releasing the tobacco companies from all current and future claims in the settlement, the States gave up both State and Federal Medicaid claims in exchange for the tobacco settlement funds. Tobacco-related Medicaid costs are at least $13 billion a year, according to independent estimates, and the States are receiving only about $8 billion a year in exchange for giving up their claims.

Current Medicaid law requires HCFA to recoup the Federal share—on average 57 percent —of all State third party liability collections, including the recent State tobacco settlements. Since the Federal government paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes the Federal government will follow the law and claim its share of the proceeds. However, the Administration proposes to work with the States and with Congress to enact tobacco legislation that, among other things, resolves these Federal claims in exchange for a commitment by the States to use tobacco money to support shared State and national priorities which reduce youth smoking, promote public health, help children, and assist affected rural communities.

Question. If it is the position of your Department and of this Administration that current law entitles the Federal government to recoup some of these settlement funds, why was the $18.9 billion not included in your budget baseline, i.e., your assumptions of Federal revenue under current law?

Answer. I'm going to have to leave budget scoring to Jack Lew, the Director of OMB. My hope as Secretary of HHS is to ensure that the Federal share of State tobacco funds are used to support shared State and national priorities which reduce youth smoking, protect tobacco farmers, improve public health and assist children. Without such legislation, States would not have to spend one penny to reduce youth smoking.

Question. If the budget submission assumes that states will somehow agree to spend $18.9 billion of their settlement funds to pay for programs that are presently the obligation of the Federal government, what basis if any do you have to assume that states will agree to such an arrangement? (i.e., has any state government indicated to your Department that they are willing to assume any Federal obligations in exchange for a relinquishment of any Federal claim to tobacco settlement funds?)

Answer. The Administration would support legislation that waives Federal recoupment in exchange for States agreeing to use the Federal share of to fund shared State/Federal priorities related to reducing youth smoking, protecting tobacco farmers, improving public health, and assisting children. The Administration does not propose to have States assume Federal obligations; we propose for States to use these funds to increase their investment in shared State/Federal priorities.

Question. If the states do not agree to assume $18.9 billion in Federal obligations, through what specific mechanism do you plan to recoup these state settlement funds, and beginning on what date? Isn't in fact the plan to cut Federal Medicaid payments to states in the same amount that you feel belongs to the Department?

Current Medicaid law requires HCFA to recoup the Federal share (on average 57 percent) of all State third-party liability collections, including the recent State tobacco settlements.

Since U.S. taxpayers paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes that the Federal government will follow the law and claim its share of the proceeds.

However, the Administration will work with the States and the Congress to enact tobacco legislation that, among other things, resolves these Federal claims in ex-

change for a commitment by the States to use tobacco money to support shared State and national priorities which reduce youth smoking, promote public health and children's programs.

It is for this reason that the Administration has delayed action on claiming the Federal share of the State tobacco settlements until fiscal year 2001 so that we can work with the States and Congress over the next year on mutually agreeable legislation.

Question. Since the Administration's position is that the Federal government will relinquish any claim to state settlement funds in exchange for being able to tell states exactly how to spend those funds, what specific programs and in what specific amounts does the Administration want states to spend their settlement dollars?

Answer. The Administration seeks to work with States and the Congress. The Administration does not seek legislation that specifies exactly how much States should spend on each program. However, the Administration believes that every state should spend at least some of their tobacco settlement funds on programs to reduce youth smoking, and other shared priorities.

Question. What assurances can you give to states that at the end of five years (i.e., after fiscal year 2004), the Federal government will help states continue to fund programs at the artificially high levels you ask them to, or do you simply expect states to dramatically cut these programs once the five-year agreement with the Federal government ends?

Answer. The Administration seeks legislation that, like last year's McCain bill, would waive recoupment of the Federal share of all years' tobacco payments, not just the next few, so long as states maintain their commitment to spend funds on shared Federal and state priorities to prevent youth smoking, protect tobacco farmers, improve public health, and assist children. As a result, there should not be a dramatic change in available resources in fiscal year 2004.

Question. Since I represent Texas, my immediate concern is for my state's roughly $17 billion settlement agreement. Can you tell me, of the $18.9 billion your Department plans to seize from the states, how much will be seized (recouped) from Texas, and during what years?

Answer. While the Administration has certain national, aggregate, expectations about the likely timing and magnitude of payments the Federal government would be required to seek from States under current law, it has not subdivided the annual estimates by State. Under current law, Texas is required to reimburse the Federal government for its share of Medicaid expenses that are reimbursed by third parties, including the tobacco companies. While the national average rate is 57 percent, the Federal government currently pays 62 percent of the cost for Texas' Medicaid program.

Question. What specific legal basis does your Department have for seeking recoupment of state tobacco settlement funds? Do you have a legal opinion from the Justice Department, the Health Care Financing Administration, or other agency to this effect? If so, could you please provide the Subcommittee with a copy of any such analyses?

Answer. Current Medicaid law requires HCFA to recoup the Federal share (on average 57 percent) of all State third-party liability collections, including the recent State tobacco settlements. Since US taxpayers paid a substantial portion of the Medicaid costs that were the basis for the State settlements, the Budget assumes that the Federal government will follow the law and claim its share of the proceeds.

On November 3, 1997, the Health Care Financing Administration sent a letter to the State Medicaid Directors, reminding them of their statutory obligation under 1903(d) of the Social Security Act. As described in the statute, States must allocate from the amount of any Medicaid-related expenditure recovery "the pro-rata share to which the United States (Federal government) is equitably entitled." This letter is attached for your information, along with the HCFA fact sheet on tobacco recoupment.

QUESTIONS SUBMITTED BY SENATOR DANIEL K. INOUYE

CHILD WELFARE TRAINING—AMERICAN INDIAN/ALASKAN NATIVES

In response to Congress' recommendation for the past 2 years that $130,000 be available to colleges that enroll American Indian and/or Alaskan Natives, the Administration states in its fiscal year 2000 proposal that 6 grants were awarded in 1998 and that the grants would be continued in 1999.

Question. Who received these grants and what was the exact dollar amount of the grants? What is the plan for continuing these grants in fiscal year 2000?

Answer. fiscal year 1998 Section 426 Child Welfare Training Grants. In fiscal year 1998, the Department funded six grants for social work training to schools that enroll American Indian and/or Alaskan Natives. The total amount of funds awarded was $439,950.

The grantees and the amount of the total individual grants is as follows:

Grantees	*Amount*
University of Utah, Graduate School of Social Work—Project Title: "Intermountain Indian Child Welfare Training Partnership"	$74,906
Arizona State University, School of Social Work—Project Title: "Traineeship in Professional Social Work Education for American Indians for Practice in Public Child Welfare Agencies"	75,000
University of Alaska-Anchorage, Department of Social Work—Project Title: "Alaska Native/American Indian Tribal/Public Child Welfare Traineeships Initiative"	69,120
University of Maine, School of Social Work—Project Title: "Social Work Education for Native American Students"	69,924
Grand Valley State University, School of Social Work—Project Title: "Social Work Education for Tribal Staff and Potential Staff"	75,000
University of Washington, School of Social Work—Project Title: "A Community Development Approach to Training Social Workers for Indian Child Welfare"	75,000

These grants were awarded for a 2-year project period. They will receive a continuation grant in fiscal year 1999 funded at the same amounts noted above. The fiscal year 2000 budget requests $7 million for child welfare training; however, specific priority areas have yet to be determined. These grantees will be eligible to compete for these funds.

PHYSICIAN OVERSIGHT OF CERTIFIED REGISTERED NURSE ANESTHETISTS (CRNAS)

Question. What is the status of your proposal to delete the requirement for anesthesiologist oversight of CRNAs for Medicare reimbursement?

Answer. The proposed rule was published in the Federal Register on December 19, 1997. The proposed rule received approximately 60,000 comments. More then 20,000 of the comments discussed physician supervision of nurse anesthetists. The contents of the final rule are still being considered.

EMERGENCY MEDICAL CARE FOR CHILDREN (EMSC)

I strongly support the Emergency Medical Care for Children program and was concerned by what I saw in the budget report. The President's Budget proposal combines EMSC with 3 other programs under the heading of Critical Care Programs. Two of these programs, Trauma Care EMS and Poison Control Centers, are new programs with no prior funding. The budget proposal recommends specific funding for each of the four programs, with EMSC receiving $15,000,000. I am concerned that if the full request of $22,500,000 is not appropriated, funding for the other programs will be at the expense of the EMSC program.

Question. How will HRSA ensure EMCS receives the recommended $15,000,000 appropriation?

Answer. While it is proposed that all four programs be included in an administrative cluster, organized under and directed from within a single branch within HRSA's Maternal and Child Health Bureau, the request for funding does not include a consolidation of existing program authorities. As such, funding would go to each program as appropriated and would not be diverted to other programs without the consent of the Appropriations Committees.

NATIVE HAWAIIAN HEALTH CARE/HUI

Question. In the fiscal year 2000 budget proposal, you indicate that the 1997 Hawaiian HUI proposal recommended by the Administration for New Start funding was not accepted due to a lack of organizational readiness to begin providing services. What specific weaknesses were identified, and what technical assistance has been provided to the HUI project to ensure they have a competitive application for the upcoming grant cycle?

Answer. The HUI proposal submitted in the 1997 Health Center new Start/Expansion grant application cycle was not selected because of lack of readiness. The HUI proposal was to support an integrated delivery system of Health Centers with an administrative support organization to receive the grant funds. At the time of application, the development of the network was still in the planning stages and would not be ready to receive funds and be operational within the required time

frame. The network corporate structure and organizational relationships had not been defined and would not be ready prior to time funding decision were to be made. Recognizing the value of the proposed integrated delivery system, HRSA provided funds to the Hawaii Primary Care Association to provide ongoing technical assistance in developing the corporate relationship between the Health Centers making up the HUI and to develop the integrated network in order for these organizations to be competitive in the fiscal year 1999 Health Center new start/expansion grant application cycle.

NATIONAL INSTITUTES OF HEALTH

STATEMENT OF HAROLD E. VARMUS, M.D., DIRECTOR

ACCOMPANIED BY:

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DENNIS P. WILLIAMS, DEPUTY ASSISTANT SECRETARY, BUDGET, DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTRODUCTION

Senator SPECTER. We will now turn to the distinguished panel from the National Institutes of Health. In the interest of time, we are going to move right ahead. Dr. Varmus has brought his own name tag up.

The National Institutes of Health has been, as I say with some frequency, the crown jewel of the Federal Government. I also add, perhaps the only jewel of the Federal Government sometimes.

I note on the budget request which had been submitted by the National Institutes of Health, and I have pressed Dr. Varmus on this in the past—the request of the NIH before the Office of Management and Budget went to work on it was $19.3 billion, which would be a very substantial increase over the $15.6 billion that we have at the present time. With the achievements at NIH, it has been the view of the Congress, with the initial work being done by the counterpart with Chairman Porter and ranking member Obey on the House side and Senator Harkin and myself on the Senate side back in the subcommittee and the full committee and the Senate and the House, to really find the funding for the National Institutes of Health.

PREPARED STATEMENT OF SENATOR HARKIN

So we welcome you here, Dr. Varmus, with a very distinguished array of scientists, and note the recent achievements on cancer and on the stem cells, and look forward to your testimony.

Senator HARKIN. Senator Specter I ask that my prepared statement be inserted into the record.

Senator SPECTER. Your statement will be inserted into the record at this point.

[The statement follows:]

PREPARED STATEMENT OF SENATOR TOM HARKIN

I want to welcome Dr. Varmus and his colleagues from NIH today. NIH is the premier medical research institution in the world. The research it funds is key to maintaining the quality of our health care and key to finding preventive measures, cures and the most cost effective treatments for the major illnesses and conditions that strike Americans.

But I must say that I am disappointed in the President's budget request for NIH. Last year, this subcommittee was able to secure a $2 billion increase for NIH—setting a course to double NIH funding over five years. The Administration's request for fiscal year 2000 is extremely short sighted when it comes to support for finding cures, more cost effective treatment and preventions for the many diseases and disabilities that hit millions of Americans every year. I hope to work closely with Senator Specter this year to build on last year's increase for NIH as we move to doubling funding for NIH over a five-year period.

One, but certainly not the only, reason that we must continue this support for medical research at NIH is the truly awe-inspiring potential benefits of stem cell research. Our Chairman has now held three hearings on the issues surrounding stem cell research. At those hearings, I have had the opportunity to express my support for this research and my concurrence with the opinion of the HHS General Counsel that research using stem cells is eligible for federal funding. Now it is time to move forward. Dr. Varmus, I expect that you will keep me updated on how you intend to encourage and support quality, ethically-sound research in this area over the coming months.

Thank you, Mr. Chairman—I look forward to hearing from our witnesses.

SUMMARY STATEMENT OF DR. HAROLD VARMUS

Dr. VARMUS. Thank you, Mr. Specter. I will be extremely brief in view of the time. I am here representing the NIH for the sixth time and pleased to be doing so.

The President is requesting $15.933 billion, an increase of $320 million over our appropriated funds for 1999. This request builds on last year's extraordinary $2 billion increase, a 15 percent increase, and keeps us just ahead, as the Secretary mentioned, of the President's 5-year plan to increase the budget of the NIH by 50 percent over 5 years.

Because time is so short, indeed shorter than we had anticipated, my statement and those of the Institute directors arrayed behind me will be submitted for the record. In those statements you will see the recounting of many recent successes in the war that NIH is waging against disease: the success we have had in gathering intelligence about biological systems and about how those systems fail, and the success we have had in testing strategies to combat the enemy in the battlefield.

The most frequent question that we have been asked in this budget season is the simple one: How are we managing the $2 billion of increased funding that we received in fiscal year 1999? In order to expedite that discussion, the Institutes and the central NIH have provided the committee with a comprehensive analysis—that you all have received—that displays the many new initiatives that we have undertaken in fiscal year 1999, initiatives that are aligned in these documents according to spending mechanism.

As you leaf through these documents, you will see a highly varied research program that exploits new advances in genetics and biochemistry, imaging technology, and many other disciplines. You will read about new means for training investigators and encouraging them to participate in biomedical sciences, including clinical scientists and those who represent computer science and engineering and chemistry and many other allied disciplines that contribute so much to the biomedical research effort.

Finally, you will see many efforts to address the major threats to the health of our own citizens and to people throughout the world.

PREPARED STATEMENT

We have been able to initiate so many programs in fiscal year 1999 because of the powerful start that this committee and your counterparts in the House and the administration have allowed us to make to the goal of increasing the NIH budget by 50 percent over 5 years. We will continue all of these programs in fiscal year 2000, and by using a conservative financial management scheme we will be able to begin even more programs, as outlined in our Congressional justification.

Mr. Chairman, my colleagues and I look forward to discussing these many new activities with you today and we will be pleased to answer any questions you may have.

[The statement follows:]

PREPARED STATEMENT OF DR. HAROLD VARMUS

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the Buildings and Facilities (B&F) Program. The President in his fiscal year 2000 budget has proposed that the B&F receive $148.4 million, a decrease of $43 million from the comparable fiscal year 1999 appropriation. This includes $40 million forward funding in the fiscal year 1999 appropriations act to complete funding for the Mark O. Hatfield Clinical Research Center.

ROLE IN THE RESEARCH MISSION

The B&F appropriation funds the design, construction, improvement, and major repair of the facilities in which the NIH conducts medical research and administers nationwide research programs that seek to improve the Nation's health. The appropriation supports the design and construction of new facilities for NIH research programs and the continuing renovation, alteration, and repair of existing facilities.

The B&F portfolio of research, administration, and associated facilities and the physical infrastructure that supports them are critical to the success of NIH's mission. Requisite facilities, properly sized, configured, equipped, and serviced enable NIH staff to work efficiently and productively. Conversely, a misfit between the state of a facility and the needs of its occupants can create costly barriers including loss of productivity and health and safety risks.

MASTER PLAN

The NIH is moving forward with a new blueprint to guide future development on the campus. The updated master plan that was approved by the National Capital Planning Commission (NCPC) in February 1996 for the Bethesda campus identifies programmatic requirements in terms of personnel and physical facilities; establishes concepts for future development and land use, buildings, utilities, open space, circulation and traffic management for the next twenty years; and illustrates how needs for laboratory and clinical research, administrative, and support space can be accommodated. An updated Master Plan for the NIH Animal Center in Poolesville was completed in the fall of 1996.

The master plan is the guiding beacon as the NIH maintains its forward pace in the midst of a sorely needed major facility improvement program. The center piece of this program is the new Mark O. Hatfield Clinical Research Center (CRC) now under construction. When completed, this combined hospital and clinical research facility will replace the 40-year-old, outmoded and deteriorated patient care wards and research space with state-of-the-science facilities designed and built to support medical research into the new century.

The Mark O. Hatfield Clinical Research Center is only part of the facility improvement story. Most of the NIH research facilities across the nation are, like the facilities the new Clinical Research Center is replacing, old, outmoded, and poorly suited to the demands of modern medical research. They lack the appropriate layout, types of electrical service, laboratory gases, telecommunications, and environmental controls needed today. Moreover, many of the facilities were built before the adoption of model building codes. Some lack fire suppression systems and other life safety systems now considered essential. Others contain asbestos, insufficient heating ventilation and air conditioning, and architectural barriers for the disabled.

Through a carefully planned and effectively managed B&F Program, the NIH is addressing these conditions at each of its sites. On the Bethesda campus, the improvement program includes replacement and some new research buildings and renovations to existing laboratory and administrative facilities. At the NIH Animal Center, the improvements are targeted toward increasing the research capacity of the center by modernizing and increasing the capacity and reliability of the utility systems and by adding laboratory animal facilities with sufficient procedure areas to support present and future animal models. At the National Institute of Environmental Health Sciences, Research Triangle Park, North Carolina, minor improvements are needed in the immediate future. In the past five fiscal years, the B&F Program has supported improvements at the Rocky Mountain Laboratory, Hamilton, Montana. This includes safety and reliability upgrades to existing infrastructure and utilities systems, as well as funds to construct a new laboratory facility to provide biosafety level 3 containment space for the conduct of multi-drug resistant tuberculosis research. At the Caribbean Primate Research Center, Sabana Seca, Puerto Rico, the budget request includes funds to perform an environmental audit related to the closure of an inactive sewer system.

MARK O. HATFIELD CLINICAL RESEARCH CENTER

The Mark O. Hatfield Clinical Research Center is an addition to the existing Warren G. Magnuson Clinical Center Complex and will house the clinical research program of the NIH. The NIH places the highest priority on the renewal of the hospital portion of the existing Clinical Center Complex. In addition to patient-related research, the existing Clinical Center Complex contains approximately 40 percent of the research space on the Bethesda campus and is the keystone of the NIH Intramural Research Program. The initial and critical phase in the renewal of this valuable resource is the Mark O. Hatfield Clinical Research Center (CRC). The new facility will contain patient care, treatment, and clinical research facilities. These new facilities replace existing laboratories, patient wards, and support facilities that have deteriorated from overuse and are not adequately serviced to meet current research requirements. The CRC will be the heart of the NIH Intramural Research Program, as the original Clinical Center Complex is now.

The state-of-the-art research hospital with 250 beds, allied clinical facilities, and adjacent research laboratories for work that is closely intertwined with patient research activities, will be located to the North of the existing Building 10 complex and ambulatory care research building. The research hospital will be approximately 610,000 square feet and will be served by an additional 250,000 square feet of new space dedicated to laboratory and program support.

The CRC project is scheduled to be completed in 2002. To meet this aggressive schedule, the CRC is currently being fast-tracked, i.e., the construction will start while the design is being developed. Site preparation work for the CRC began in September 1997 and is nearing completion. It includes demolition of existing structures on the project site; modification of the existing south entrance to the Clinical Center to facilitate construction of the new CRC on the north side of the Clinical Center; relocation of utilities; and realigning Center Drive, the principal roadway on the NIH campus. In the next year, significant progress will be made: the design will be fully completed; the excavation and the building foundation will be substantially completed; and construction of the building structure will be underway. To maintain the CRC on schedule and within budget, a cost and schedule containment program has been developed and implemented. This includes a formal value engineering analysis, reviews by outside experts, and the development of a project cost schedule.

CENTRAL VIVARIUM

Studies in the NIH master plan document the need for new replacement research facilities on the site of the present day central animal facilities, which is outmoded, expensive to maintain, and inadequate to sustain modern animal research. In order to meet the need for improved, expanded animal facilities, a new central vivarium is planned. The fiscal year 2000 request will initiate the design of a multi-level animal facility to consolidate ongoing programs in the sprawling and aging Building 14 and 28 complex, as well as to meet the research needs for emerging animal models, including non-mammalian models, with a modern and compact structure housing common functions. The new facility will meet the majority of the needs of the NIH intramural program on the NIH Bethesda campus primarily in one centralized location. This crucial project will support animal research and is an integral component of a major objective of NIH's Master Plan to better utilize its land by creating available space for the construction of other potential facilities in the future.

ESSENTIAL SAFETY AND HEALTH IMPROVEMENTS

The NIH continues to place a high priority on safety and health requirements necessary to meet critical infrastructure and environmental improvements to existing facilities to comply with safety and health regulations and support ongoing research programs. As buildings age and health and safety guidelines and regulations change, renovations and upgrades are necessary to ensure the safety and health of the building's occupants. The projects within the Essential Safety and Health Improvement initiatives address these issues. Without the improvements funded by this portion of the Buildings and Facilities appropriation, the NIH eventually would not be able to continue to safely use many of its older facilities. Valuable research capacity would be lost, laboratories would have to be shut down, animal facilities closed, and research activity curtailed. Therefore the projects funded by this portion of the appropriation are vital in order for the NIH to continue to use virtually all the buildings on the main campus; NIHAC; and facilities in Frederick; Baltimore; Hamilton, Montana; and other satellite locations.

The fiscal year 2000 request for the Essential Safety and Health Improvements initiatives includes: the continued phased removal of asbestos-containing materials from various NIH buildings; the implementation of the plan to correct fire and life safety deficiencies in NIH buildings on the campus and at the NIH Animal Center; the construction of the upgrade of the utility infrastructure at the NIH Animal Center, Poolesville; the ongoing rehabilitation of NIH animal research facilities; and continuation of the environmental assessments/remediation program. All of these projects are driven by federal and local regulations, policies and national accreditation requirements.

REPAIR AND IMPROVEMENT PROGRAM

The Repair and Improvement (R&I) program supports major repairs, maintenance and improvements to the physical plant that supports the main NIH campus in Bethesda, as well as to field stations that are the responsibility of the NIH. The goal of the R&I program is to sustain efficient and effective facility performance throughout the life cycle of the facility to meet ongoing requirements of the NIH research mission. The costs for some of the projects are recurring and substantial. For example, roofs, roads, structures and building and underground utilities require regularly scheduled repairs, ad hoc repairs and maintenance to preserve or achieve reliable and safe conditions. For other projects, the costs are largely one-time, often unpredictable expenditures for major items of equipment requiring emergency repair or replacement such as transformers, chillers, and cooling towers.

RENOVATIONS AND SYSTEM UPGRADES

The fiscal year 2000 B&F request also provides funds for the Building 10 Transition Program which support modifications within the existing Clinical Center Complex to provide effective integration of the new addition and the remaining diagnostic, treatment, support, and research areas housed in the existing building. In addition, the NIH needs to construct an additional electrical substation and upgrade the existing west substation in order to support the new CRC as well as other new facilities coming on line.

FISCAL YEAR 2000 BUDGET SUMMARY

The fiscal year 2000 request for Buildings and Facilities is $148.4 million. This amount includes $40 million appropriated in Public Law 105–277 for the Mark O. Hatfield Clinical Research Center, the fourth and final funding increment to complete construction. The B&F request totals $30.5 million for essential safety and health improvements composed of $3.5 million for the phased removal of asbestos from NIH buildings; $5 million for the continuing upgrade of fire and life safety deficiencies of NIH buildings; $16 million for the upgrade of the utility infrastructure at the NIH Animal Center, Poolesville; $5 million for the continued support of the rehabilitation of animal research facilities; and $1 million to continue the program of environmental assessments and remediation. In addition to the essential safety and health improvements, the fiscal year 2000 request includes: $10 million to initiate the design of the Central Vivarium; $7.2 million for the Building 10 transition program; and $10 million for the construction/upgrade of electrical substations. The fiscal year 2000 request also includes $50.7 million for the continuing program of repairs, improvements, and maintenance that is the true keystone of the B&F program.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The activities of the B&F Program are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. RUTH L. KIRSCHSTEIN

Mr. Chairman, Members of the Committee: We are pleased to be here today to discuss the fiscal year 2000 budget request for the Office of the Director (OD). As

you know, the OD provides leadership and coordination in the areas of policy and management related to the research activities of NIH, both extramural and intramural. In addition, the OD is responsible for a number of special programs, established within its purview, and for leadership and management of centralized support services and functions essential to the operations of the entire NIH.

The President in his fiscal year 2000 budget has proposed that the OD receive $218.2 million, an increase of $5.1 million over the comparable portion of the fiscal year 1999 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for the OD is $262.7 million, an increase of $6.2 million over the fiscal year 1999 appropriation. Funds for OD efforts in AIDS research are included within the Office of AIDS Research budget request.

The NIH, comprising some 24 Institutes and Centers, (or ICs), conducts a vast program of medical research and training designed to advance medical knowledge and to sustain the Nation's medical research capacity. Attainment of these goals results in improved health for all Americans, enhancing the quality of life for our citizens, and benefitting the Nation's economy.

As has been expressed throughout these hearings, NIH is in a unique position to address public health needs and pursue promising scientific opportunities in the prevention, diagnosis, and treatment of disease. The OD mission is to provide the means—the leadership and administrative and management activities—whereby the specific research ICs can conduct their activities in the core program areas of research, research training and career development, and the support of research facilities. The OD provides a structure and framework for the conduct of the activities of the ICs in a manner that is responsive to promising research opportunities and technologies, yet addresses public health needs. Specifically, the OD guides and supports research by setting priorities; allocating funding among these priorities; developing policies based on scientific opportunities and ethical and legal considerations; maintaining peer review processes; providing oversight of grant and contract award functions and of intramural research; communicating health information to the public; facilitating the transfer of technology to the private sector; and providing fundamental management and administrative services such as financial accounting and personnel, property, and procurement management, administration of equal employment practices, and plant management services, including environmental and public safety regulations of facilities. The principal OD offices providing these activities include the Office of Extramural Research (OER), the Office of Intramural Research (OIR), and the Offices of: Science Policy, Communications, Legislative Policy and Analysis, Equal Opportunity, and Management. This request contains funds to support the functions of these offices.

To further influence research activities and to address targeted public health needs and specific components of medical research, the OD maintains several trans-NIH offices and programs that focus on a particular aspect of research and foster and encourage research in that particular area. These OD offices address a variety of health needs and research areas, including programs to coordinate prevention activities in the ICs and to improve the health of women and minority populations; activities to examine the use of dietary supplements; research related to social and behavioral patterns in the maintenance of health; and efforts to promote research on rare diseases. I will now discuss the budget requests of these trans-NIH offices in greater detail.

It should be noted that, as enacted by legislation for fiscal year 1999, research related to complementary and alternative medicine, previously supported in the OD, is now being undertaken by the newly established National Center for Complementary and Alternative Medicine (NCCAM).

The budget requests of the remaining trans-NIH offices are presented below.

THE OFFICE OF RESEARCH ON MINORITY HEALTH AND THE NIH MINORITY HEALTH INITIATIVE

Minorities at all stages of life suffer poorer health and higher rates of premature death than do non-minority populations. The Office of Research on Minority Health (ORMH) was established to address these health disparities and to promote medical research aimed at improving the health status of minority populations throughout their lifespan. The Office also supports programs to expand the ability of minority scientists to participate in all aspects of medical research. As such, the budget request supports numerous collaborative activities with the ICs in the areas of research, research training and career development. Specifically, ORMH will support research activities by providing grant supplements for research on diseases that disproportionately affect minorities in the U.S., such as lupus, asthma, and hypertension, and, in developing countries, such as malaria, tuberculosis and AIDS.

The Minority Health Initiative (MHI) is a comprehensive program with a focus on developing and testing interventions that will reduce the disproportionate burden of disease among minority populations and developing successful strategies to promote health behaviors across the life span. Collaboration with the ICs focuses on research training, across the educational pipeline, to ensure the appropriate representation of minorities in health research related careers. MHI sponsors specific projects to develop therapies for sickle cell disease, to develop prevention and control strategies for prostate cancer, to address diabetes among Hispanics and Native Americans, to treat hypertension among Asian and African Americans, and to support initiatives to decrease injury and death due to violence in minority youth, reduce unintended pregnancy in minority women, and support initiatives to reduce infant mortality in inner city populations.

Research training programs include the Bridges to the Future program, the Minority International Research Training (MIRT) program, and the Comprehensive Partnerships for Mathematics and Science Achievement (CPMSA) program. Through the ORMH, NIH stimulates and fosters minority research activities among the ICs, and is evaluating these activities, through review by the Advisory Committee on Research on Minority Health which met twice during the fiscal year 1998–1999 period. Presently the committee is engaged in the development of a comprehensive strategic plan for minority research and training which it intends to submit to the NIH Director at the end of fiscal year 1999.

THE OFFICE OF DISEASE PREVENTION

Within the OD, the Office of Disease Prevention (ODP) has several specific programs that strive to place new emphasis on the prevention and treatment of disease.

The Office of Dietary Supplements (ODS) stimulates research on the use of dietary supplements, to benefit health and prevent disease. During fiscal year 2000, the ODS will continue to develop the Botanical Centers Initiative. In fiscal year 1999 a Request for Applications was issued. It is expected that funds for this activity will be awarded in fiscal year 1999. The purpose of the initiative is to foster interdisciplinary research to evaluate the health effects of botanicals. The ODS will continue to support investigator initiated studies through Research Enhancement Awards Program (REAP) awards and joint program announcements with the ICs. These address areas such as thiamine deficiency, use of vanadium salts and antifolates; and protocols that investigate the effect of dietary supplements on antibiotic-induced hearing loss and loss of bone density in athletes. ODS will continue public-oriented information pages on specific dietary and botanical supplements. Finally, the ODS will continue to conduct conferences and workshops to encourage new research initiatives in this field.

To address unrecognized public health needs, the Office of Rare Diseases develops and disseminates information on rare diseases and conditions and forges links between investigators having ongoing research activities in this area. The ORD supports workshops and symposia to stimulate research interest and to identify research opportunities related to rare diseases. These workshops have resulted in a determination of research priorities, the development of research protocols, and criteria for diagnosing and monitoring rare disorders such as head and neck cancers, AIDS related malignancies, sleep control, hereditary ataxias, and unusual palsies and dysplasias. In fiscal year 2000, the ORD, with the National Human Genome Research Institute (NHGRI), will support an information center to respond to the numerous requests for information about rare and genetic disorders. In addition, the ORD, with the NIH ICs and the FDA Center for Biologies Evaluation and Research (CBER) will continue to pursue its initiative to develop gene therapies for rare monogenic diseases.

THE OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH (OBSSR)

Many of our most serious health concerns are related to behaviors. Recognizing this, the Office of Behavioral and Social Sciences Research (OBSSR) was established to address the role of behavior and social factors in the prevention and management of disease. The OBSSR increases the scope of, and support for, behavioral and social science across all of NIH. The office develops initiatives to stimulate research in these areas and to ensure that findings from this research are disseminated to the public.

In conjunction with the NIH ICs, the OBSSR is focusing on three trans-NIH initiatives: Innovative Approaches to Disease Prevention through Behavior Change; Educational Workshops on Interdisciplinary Research; and the Mind/Body Research Initiative. The Behavior Change Initiative encourages the study of innovative be-

havioral interventions that address risk factors such as tobacco use, lack of exercise, improper diet and alcohol abuse. The Interdisciplinary Workshops Initiative builds on previous successful efforts and is designed to introduce young investigators in one discipline to the concepts and methods of another discipline with a goal of facilitating interdisciplinary research collaborations that cross sociobehavioral and biomedical studies.

The Mind/Body Initiative has been developed in response to Congressional concern about the impact of stress on numerous medical conditions, and will establish centers that will foster mind/body approaches to health. Basic research as well as clinical applications will be supported and will focus on three areas: (1) the influence of beliefs, attitudes, and values on physical health; (2) the determinants or antecedents of health-related beliefs, attitudes, or values; (3) and stress management approaches to disease treatment and prevention. The OBSSR and 12 NIH ICs, are cosponsoring this initiative utilizing specialized center awards. Applications have been solicited under an RFA and are to be submitted for review by April of 1999.

THE OFFICE OF RESEARCH ON WOMEN'S HEALTH

The Office of Research on Women's Health (ORWH), is the focal point for women's health research at NIH and strives to ensure that research supported by NIH addresses health concerns of women, that women are appropriately included as subjects in research protocols and clinical trials, and that women are encouraged to pursue careers in medical research. The Office has revised its science-based agenda, Research on Women's Health for the 21st Century, based on a series of public hearings and scientific workshops. ORWH will use its funds to stimulate, initiate, and expand women's health research by supporting research grants, RFAs, Program Announcements, and Research Enhancement Awards in the priority areas identified by this report. In fiscal year 2000, ORWH will implement selected research initiatives and programs including an initiative on the molecular/genetic and physiological bases for sex differences related to health and disease; research on renal and urogynecologic disorders; and gastrointestinal and digestive diseases. Additional research efforts will be focused on: allergic, immune and autoimmune diseases such as lupus, arthritis and chronic pain, heart disease, alcohol and drug use, reproductive health and prevention of diabetes. The ORWH will also continue to develop and implement programs to advance the careers of women in science and to provide opportunities to increase the number of young investigators in multidiciplinary basic and clinical research related to women's health.

OTHER OD ACTIVITIES

The OD also supports a number of additional NIH programs that promote scientific research and enhance research career development.

The Office of Extramural Research (OER) coordinates the Academic Research Enhancement Award (AREA) program that provides grants to institutions that award degrees in health sciences but are not major recipients of NIH grant funds. These awards enable college students to participate in research projects and encourages them to pursue careers in medical research. OER also sponsors the Extramural Associates Research Development Award (EARDA) program that provides competitively awarded grants to institutions that have a significant enrollment of underrepresented minority students who, with their faculty, participate in medical research programs. The grants are designed to provide faculty at these institutions with skills needed to become more competitive in obtaining Federally sponsored research funds.

The NIH, through the Office of Intramural Research (OIR), maintains loan repayment and scholarship programs as important instruments for recruiting high quality candidates in basic and clinical research positions. The request contains funds for the NIH Clinical Research Loan Repayment Program and the Undergraduate Scholarship Program, both for individuals from disadvantaged backgrounds; and for the Loan Repayment Program for General Research. Each program provides for the payment of educational costs in return for specific commitments of service in NIH's intramural research facilities.

The Office of Science Policy coordinates several science education activities that benefit both students and teachers and encourage students to consider careers in research. Further, through OSP, the NIH will expand its role in addressing science policy issues related to ethical concerns by coordinating the enhanced functions of the NIH Recombinant DNA Advisory Committee, and the activities of the Secretary's Advisory Committee on Genetic Testing and the Secretary's Advisory Committee on Xenotransplantation.

The request also includes funds for a Discretionary Fund to permit the Director to respond to new and emerging high priority research opportunities such as vaccine study, gene mapping and imaging.

MANAGEMENT IMPROVEMENTS

Striving to maximize administrative effectiveness, NIH is continuing efforts to implement the recommendations of the comprehensive study of administrative practices and costs undertaken at the request of the Subcommittee. These endeavors are expected to enhance the overall efficiency and effectiveness of the agency's business operations, in order to ensure that NIH's first-rate research enterprise is supported by exemplary administration. The Director of NIH has appointed an Implementation Oversight Committee (IOC) to monitor implementation and make recommendations to him. This Committee is co-chaired by the Director, National Institute of Dental and Craniofacial Research and the NIH Deputy Director for Management (DDM) and includes representatives of the Executive Officer, Intramural Research and Administrative Officer communities within the ICs. Particular emphasis is being given to high priority areas such as accounts payable, property management, procurement, personnel delegations, and information technology management.

The activities of the OD are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

The fiscal year 2000 budget request for the Office of the Director is $218.2 million.

PREPARED STATEMENT OF DR. RICHARD D. KLAUSNER

Mr. Chairman and Members of the Committee: This has been a year of real progress in cancer research. For the past three years in appearing before you, I have emphasized the dramatic changes in the science and technology of cancer research, changes that we at the National Cancer Institute (NCI) are fostering and facilitating. We are all convinced that these changes can and will be applied to reducing the burden of cancer and that they will accelerate the continuing reduction in cancer incidence and mortality that we first reported two years ago.

ADVANCES IN CANCER TREATMENT AND PREVENTION

This year, I would like to illustrate some of the tangible advances made just over the past year in the prevention and treatment of specific cancers. Of course, this only represents a fraction of what we do in order to understand the causes and nature of cancer. It is fitting to report on clinical trials results in this, the 50th anniversary of the introduction of the modern, randomized controlled trial. In many ways, these trials are the culmination of the research pipeline. They establish the real value of innovation and change the practice of medicine to benefit people with or at risk for cancer. Let me highlight a few examples which illustrate several important themes. First, we are beginning to approach the prevention of cancer in addition to its treatment. Second, we are continuously optimizing even our conventional therapies in order to improve patient outcome. Third, we are beginning to tailor therapy to more precise diagnostic categories of cancer, which is made possible by a new age of molecular diagnostics. Fourth, we have begun to test novel therapies targeting the molecular machinery of cancer, heralding the future of cancer prevention and treatment.

This year, we reported the successful results of the first major cancer prevention trial carried out by one of the NCI-funded clinical trials group, NSABP. It is an example of a mechanism-based intervention aimed at preventing this common cancer. By treating women who have elevated risk for breast cancer with a partial estrogen antagonist, tamoxifen, a 50-percent reduction in incidence of breast cancer was observed over the course of the study. There was a 70 percent reduction in breast cancer incidence for those breast cancers expressing estrogen receptors, whereas there was no change in incidence of breast cancers that lacked this receptor which is the molecular target for the drug. This study showed that we can reduce the risk of breast cancer. Much remains to be studied and tamoxifen is far from perfect in

terms of its effectiveness and its side effects. It is, however, an important and landmark beginning.

The optimization of existing therapies continues to be an important approach to improving the outcome for cancer patients. Years of clinical trials to optimize chemotherapy regimens for children with acute lymphocytic leukemia (ALL) have resulted in a current cure rate of 75–80 percent. About 20 percent of children with ALL have poor prognostic characteristics and a much bleaker outcome. Results of a new trial using a modified chemotherapy regimen has resulted in a 70 percent drop in the rate of treatment failures in these high risk children under 10 years of age; these children have a 5-year event-free survival of 84 percent with this new regimen.

Nasopharyngeal cancer is relatively rare in the United States but quite common in Asia. Chinese American men have a 15–20 fold higher rate of this cancer than white American men. While nasopharyngeal cancer has been known to be responsive to radiotherapy or chemotherapy, a trial comparing the former to a combination of radiotherapy plus Cis-Platin + 5-FU was stopped early because of profound benefit. The 3-year survival in the radiotherapy alone group was 47 percent, whereas, the combined group had a 78 percent 3-year survival, and a 60-percent reduction in mortality.

DIFFERENTIAL RESPONSE TO THERAPY

Why some patients respond to a given therapy and others, with ostensibly the same disease, do not, is a central puzzle we are beginning to solve. One likely explanation is that the responders actually have a different disease than the non-responders. In a recently reported series of studies, one explanation for outcome differences in breast cancer has apparently emerged. About 30 percent of breast cancers make too much of a protein called, HER2/neu. These cancers appear to be more aggressive and new studies showed that these cancers respond significantly better to elevated doses of anthracycline drugs than cancers that don't overexpress this protein. This conclusion came from the analysis of several breast cancer treatment trials that were not originally designed to answer the question about the role of HER2 in the response to therapy. These subsequent analyses were done in order to explain why some women responded better to higher doses of therapy while others did not. Critical studies such as these require that scientists who have new ideas and new technologies have access to tissue samples that are linked to important clinical data. Over the past year, we have created a new approach to funding more of these important correlative studies and have developed a new set of mechanisms to expedite interactions between researchers with good ideas and researchers with access to tissue banks.

One of the ultimate goals of cancer research is to uncover the molecular machinery of each cancer in order to target prevention and therapies to that machinery. The great hope is that such targeted approaches will prove to be both more effective and less toxic than our current approaches. This past year, based upon clinical trials results, the FDA approved the first two monoclonal antibodies, Herceptin® and Rituximab,® for the treatment of cancer. Each is directed at a molecule expressed on the surface of specific types of human cancer.

Herceptin® is directed against HER2, a protein discovered almost 20 years ago, and proposed as a potential therapeutic target almost 15 years ago. This new drug was tested this year against metastatic breast cancer, the most deadly and least treatable stage of this disease. When such patients are treated with the drug taxol, only 16 percent experience a clinical response of tumor shrinkage. However, with the addition of Herceptin,® 42 percent of patients have anti-tumor responses and these women experience a statistically significant prolongation of survival. As hoped for, Herceptin® added relatively little toxicity. Now, we are working with the company that developed Herceptin to rapidly expand the evaluation of this agent in earlier stages of breast cancer and in the treatment of other cancers, such as ovarian, which overexpress the target of this drug.

Non-Hodgkin's lymphoma is newly diagnosed each year in over 55,000 Americans. It is one of the few cancers whose incidence has been rising. Fifty percent of those diagnosed will die of their disease and, as with so many cancers, we need new, more effective and less toxic therapies. Twenty years ago, basic immunologic research identified a molecule, CD20, specific to the surface of B lymphocytes which was also highly expressed on the surface of most lymphomas. An antibody directed against this molecule was shown to be able to kill cells and thus began a 15-year odyssey to engineer an anti-CD20 antibody which could be used in treatment. Last year, such an engineered antibody, Rituximab,® was approved by the FDA. It is becoming the treatment of choice for patients with low grade lymphoma. It is as effective at

inducing remission as chemotherapy but with very little toxicity. As with all such advances, we do not stop there but use these findings as a stepping stone for further development. Multiple clinical trials are underway to broaden the cancer targets for Rituximab,® to combine it with chemotherapy and, in a very promising development, to arm the antibody with radionuclides. Early phase II studies with I^{131}-labelled anti-CD20 show it to be five times more effective at inducing long-term disease-free survival than the best available chemotherapy. These promising results will need to be validated in definitive clinical trials with the hope that this new example of molecular therapy will profoundly alter the outlook for these cancer patients.

These examples are just a sampling of recent clinical trials culminations. Our clinical trials not only examine new treatment regimens but also evaluate ways of reducing toxicity, decreasing pain and suffering and improving the short and long-term quality of life for cancer survivors.

We are now instituting the first major reform and restructuring of the NCI national clinical trials system since it was established 40 years ago. The goal of this restructuring is to make this national resource function even better by:

(1) creating a new peer review system that will allow and encourage any scientist to propose the best ideas for large-scale clinical trials,

(2) providing a complete menu of clinical trials options that will be available to all patients and all participating physicians,

(3) improving the operating characteristics of the clinical trials system, reducing barriers to participation, speeding the conduct of the trials and enhancing the efficiency and effectiveness of these important studies,

(4) moving to adequately fund this research system, and

(5) improving our communication processes to provide everyone with comprehensible information about clinical trials.

These changes will mean more clinical trials culminations over the next several years. This fiscal year, we have provided a 30 percent increase in funding to our national clinical trials system to enable these changes. Among other changes, this will allow us to increase the number of new trials initiated and to address more questions within all of our trials.

We have also restructured our clinical trials capabilities within our intramural research program. This coming year, we intend to initiate definitive clinical trials to test the benefit of novel vaccine therapies directed against non-Hodgkin's lymphoma and melanoma, the two major cancers whose incidences are rising in the U.S.

Clinical trials are the culminations of the research pipeline that must be filled, if we are to build on the progress made to date.

IMPROVING CANCER DETECTION

Two years ago, we set up the Cancer Genome Anatomy Project (CGAP) to systematically identify the gene expression patterns that characterize human cancer. It is time now to begin to apply the gratifying progress of this project in order to develop new molecular classification schemes for patients with cancer. If successful, this will fundamentally change our approach to diagnosis, to the choice of therapy and to our ability to predict patient outcome. The Director's Challenge is a $50 million program to challenge the scientific community to accomplish just that and to deliver a new generation of diagnostic and prognostic practices to patients with cancer.

We are anxious to realize the dream of having sensitive and accurate tests to detect cancer early when it is most curable. CGAP has enabled the discovery of literally hundreds of potential markers for cancer over the past two years. For example, one year ago, we knew of no potential unique marker for ovarian cancer. Today, CGAP has provided 400 candidates ready to be tested. With the new funds we received this year, we are establishing the Early Detection Research Network to, for the first time, create a national research infrastructure to rapidly develop and test such potential markers for cancer. We are hoping that such tests will give us accurate, predictive and simple blood tests for all types of cancers.

The ability to detect, diagnose and evaluate cancer by imaging is a critical part of our approach to these diseases. We have never had a rapid way to evaluate the constantly changing technologies within the context of clinical trials. To remedy that, this year, we established the diagnostic imaging research network. This network will begin by addressing important clinical questions, such as defining the role of CT scanning and magnetic resonance imaging in the staging of women with cervical cancer.

There is a great need to assure that we fill and expand the pipeline of new agents for the prevention and treatment of cancer. This past year, we initiated a new program called RAID (for Rapid Access to Interventional Development) in order to fund

the rapid transition of new therapeutic reagents from the laboratory to the clinic after rigorous peer review in order to identify the most promising proposals. In its first year, RAID will fund 20–30 new therapeutics for such rapid development. Due to its initial success, we hope to be able to expand RAID and are also adding a new program called RAPID to offer the same process for agents aimed at preventing cancer.

Progress against cancer takes place through both the development of knowledge and of new technologies. New technology often enables the discovery of new knowledge as well as the application of that knowledge to people with, or at risk for, cancer. Evaluating, reviewing and funding research aimed at acquiring new knowledge requires different approaches than for technology development. For these reasons, this year, we created a new grant mechanism called the Phased Innovation Award which is already proving to be a highly sought after award tailored to technology development.

NEW EFFORTS IN 1999

New resources over this past year has enabled us to initiate a wide range of new research programs and projects. These include new programs in tobacco-related research, initiatives in basic biobehavioral and health communications research and a variety of programs aimed at more rapidly translating basic discoveries to clinical testing in prevention, detection, diagnosis and treatment.

The progress we are making in cancer research does not equally reach all Americans. Minorities and the underserved often have higher incidence and mortality rates and poorer outcomes. The NCI supports an extensive research program aimed at identifying and explaining the unequal burden of cancer in our diverse society. This year, we will expand our support of cancer control and research infrastructures in minority and underserved communities as one component of addressing the unequal cancer burden.

We have improved and enlarged our programs to monitor cancer burden and to identify environmental factors that may contribute to that burden. This year, we will publish, for the second time, a 25-year survey of cancer mortality rates, cancer-by-cancer, for all 3000 U.S. counties. This will serve as the basis for our ongoing search for clues to environmental, regional and occupational causes of cancer.

A two-year strategic effort to redesign our training and career development programs aimed especially at strengthening clinical research, multi-disciplinary training and training opportunities for minorities and the underserved, has begun to be implemented with a 30 percent increase in dollars aimed at training and career development in fiscal year 1999 over fiscal year 1998.

Our Cancer Centers Program which was redesigned two years ago, has grown to include 5 new centers in parts of the country which had not had NCI-designated cancer centers over the past two years and we expect to fund 2–4 new centers in the current year.

Finally, a 15 percent increase in dollars in the 1999 research projects grants pool is enabling us to fund approximately 400 additional projects and a total of 1229 competing grants this year, including our AIDS research program.

This year, the President has proposed a 2.4 percent increase in the NCI cancer budget to $2,732,795,000. This will allow us to continue to support the many initiatives that I have outlined for you. Funds for AIDS research are included with the request of the Office of AIDS Research.

The activities of the NCI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997.

PREPARED STATEMENT OF DR. CLAUDE LENFANT

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Heart, Lung, and Blood Institute (NHLBI) for fiscal year 2000, a sum of $1,759.8 million, an increase of $41.2 million above the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, the total support proposed for NHLBI is $1,825.8 million, an increase of $42.7 million over the comparable fiscal year 1999 appropriation. Funds for NHLBI efforts in AIDS research are included within the Office of AIDS Research budget request.

The activities of the NHLBI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this

performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

FISCAL YEAR 1999 INITIATIVES

We are very appreciative of the support provided by the Committee for fiscal year 1999. Let me begin by describing some new programs that we have put in place—added efforts that would not have been possible in the absence of the generous increment in appropriated funds.

The NHLBI has expanded its program of specialized centers of research in pediatric cardiovascular disease. Congenital heart disease, the most common type of birth defect, affects about 32,000 newborns annually according to the National Hospital Discharge Survey. In addition, many children in the United States suffer from acquired cardiovascular disorders. An increase in the number of centers and in the funding level for this program will ensure that full advantage is taken of the extraordinary research opportunities that exist to address this pressing public health need.

The Study of Coronary Revascularization and Therapeutics Evaluation (SOCRATES) will address treatment of patients with chronic coronary heart disease who suffer from cardiac ischemia. Both pharmacologic and revascularization approaches are widely used to relieve anginal pain, but evidence suggests that a more aggressive approach that goes beyond symptom relief and aims to maximize blood flow to the heart muscle may be beneficial. This trial will examine the benefits of such an approach in terms of morbidity and mortality, quality of life, and health care costs.

Although diabetic patients suffer greatly from their primary illness, most die of cardiovascular disease, not of diabetes itself. The Institute has issued requests for proposals to conduct the Prevention of Cardiovascular Disease in Diabetes Mellitus trial. This 9-year study seeks to determine whether the occurrence of major cardiovascular events in type 2 diabetes patients can be reduced by one of several regimens to control blood sugar, lipid, and blood pressure levels. It addresses an urgent public health problem that is expected to become even greater as the number of Americans who are obese, who are elderly, or who are members of minority groups with a particular susceptibility to diabetes grows.

A new program of basic research will bring the modern approaches of molecular medicine to bear on the problem of abdominal aortic aneurysm. This increasingly common vascular disease often goes undetected until a rupture occurs, often with fatal consequences. Investigators will explore factors involved in its initiation, progression, and rupture, with the ultimate goal of uncovering effective strategies for management and prevention.

Despite major advances in understanding asthma and developing new therapeutic modalities to control symptoms and prevent exacerbations, effective therapies are not widely used in the pediatric health care community. Moreover, the long-term effects and side effects of asthma medications in children, especially children under 12 years of age, are not well understood. An interactive Pediatric Clinical Asthma Research Network is being established to evaluate current and novel therapies and management strategies for children with asthma. It is anticipated that one outcome of the network—an approach we have used for adult asthma research—is to promote rapid dissemination of findings to the health care community. The Institute has also begun a program of basic research to uncover the mechanisms underlying changes in the structure and composition of the airways that accompany asthma, in the expectation that gains in fundamental knowledge will eventually suggest new strategies for prevention.

Strong interest continues in the research finding, reported last year, that retinoic acid stimulates growth of new air sacs, or alveoli, in the lungs of mice who have experimentally induced emphysema, and this work is now being extended to nonhuman primates. Moreover, the NHLBI has launched a program of clinical centers to conduct preliminary studies preparatory to testing this approach in human patients. A new program of basic research has also been set in motion to improve understanding of how alveolar formation is regulated at the genetic, cellular, and molecular levels. Its findings are expected to lead ultimately to clinical interventions to help the patient who has an inadequate number of alveoli as a result of aberrant lung development, injury, or disease.

In the area of blood safety, a new program will focus on development of assay methods for the detection of Creutzfeldt-Jakob (CJD) disease. This rare, but invariably fatal, disease causes degeneration of the central nervous system. Recent reports of blood donors who were diagnosed with CJD after having made a number of donations stimulated concern about possible transmission by blood components, but answers to that and other questions about CJD have been impeded by the lack of an assay system. The goal of this initiative is to develop a system capable of screening donated blood and donors of organs or tissues.

Currently available treatments for Cooley's anemia involve lifelong transfusions of red blood cells every 2 to 4 weeks, but the transfusions also result in toxic amounts of iron being absorbed by the body. Removal of the excess iron is an expensive, burdensome procedure that often leads to poor patient compliance. The Cooley's anemia research community has, for some time, urged the NHLBI to establish a clinical research network to facilitate exploration of alternative and less onerous treatments and, ultimately, find a cure for Cooley's anemia. The Institute is pleased that it is now able to move forward in this important area.

RESEARCH ADVANCES

According to the National Hospital Discharge Survey, more than 800,000 revascularization procedures are performed in the United States each year, either through coronary artery bypass grafting or angioplasty. These treatments extend and improve life, but they are very expensive and not always successful. Just recently, scientists demonstrated that by injecting into the heart DNA that encodes for a vascular growth factor, blood flow could be restored in patients with severely blocked coronary arteries. As the safety and reliability of this approach become more firmly established, it is expected to revolutionize our ability to provide cost-effective treatment to many patients with established coronary disease.

The mature human heart has no ability to regenerate cells that die; therefore, the only hope for patients with end-stage heart failure is heart transplantation—an option that carries considerable risk and is quite limited by the unavailability of donor hearts. However, promising new approaches are emerging from basic science laboratories. Scientists have been successful in transplanting leg muscle cells of rabbits into damaged areas of their hearts. Remarkably, these skeletal muscle cells engrafted and took on the appearance and function of heart muscle cells. With further development, such an approach could usher in a new era of treatment options for an increasingly prevalent, ultimately fatal, disease.

For some time, infections have been implicated in the development of atherosclerosis, and now it appears that this may be the case with asthma, as well. Researchers have found Mycoplasma pneumoniae, the microorganism responsible for what is colloquially termed "walking pneumonia," in the airways of a large proportion of adults with chronic asthma. Moreover, antibiotic treatment of such patients improves lung function, reduces inflammation, and perhaps eases debilitating symptoms as well. This surprising discovery suggests an entirely new approach to asthma treatment and prevention.

The field of blood stem cell transplantation illustrates the rapid pace at which science is moving. When I became director of the NHLBI in 1982, the notion that transplantation could be done successfully with marrow from an unrelated donor seemed speculative, at best. Ten years later, the feasibility of unrelated-donor transplantation was well established, and the search was on for alternative sources of stem cells. At that time, we provided funding for a futuristic proposal from the New York Blood Center to collect and bank the umbilical-cord blood of newborns that is usually discarded, but is rich in stem cells. We now have the results of the first 562 transplants performed using this cord blood, and they are truly remarkable. Success rates of cord blood transplants—even when donorrecipient tissue types were imperfectly matched—were comparable to the outcomes achieved with closely matched unrelated-donor marrow transplants. Because cord blood is readily available, can be collected at no risk to the newborn donor, and is less likely than bone marrow to transmit infection, this approach may provide new hope for thousands of patients in need of a transplant.

Meanwhile, we have much reason to believe that stem cell transplants may offer a solution to the suffering of patients with severe sickle cell disease. Among 49 children who received bone marrow stem cells from matched sibling donors through an NHLBI-supported research program, 94 percent have survived to date and the vast majority have experienced considerable improvement in their disease. Quite recently, medical history was made when a 12-year-old boy received the first cord blood transplant for sickle cell disease. We are following progress in this area close-

ly, in the expectation that a cure for sickle cell disease may ultimately be within reach.

PREVENTION AND EDUCATION

Despite the many exciting scientific opportunities that promise future benefits, we have not lost sight of our public health mission and our imperative to use the knowledge that we have available today to benefit the people of this country. A recent analysis of data from the Framingham Heart Study is giving new momentum to our research and education/prevention efforts. It revealed that one out of every two men, and one out of every three women, in the United States will develop coronary heart disease at some point during their lifetimes. This constitutes a staggering burden on the nation, when one considers the premature death, the loss in quality of life, and the expense of hospitalizations, medications, and procedures to treat this disease. Moreover, the study indicates that even among people who reach age 70 with healthy hearts, one-third of men and one-fourth of women will develop coronary heart disease during their remaining years. Thus, the myth that those who navigate their middle years disease-free are somehow invulnerable is just that. The message from these findings is that prevention of coronary heart disease is everybody's business, that it must start early, and that it must continue throughout life.

To ensure that the maximum benefit is derived from our research programs, we frequently and critically assess new discoveries and incorporate them into our recommendations for health care practitioners, patients, and the public. Last summer, for instance, we released The Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults: The Evidence Report in cooperation with the National Institute of Diabetes and Digestive and Kidney Diseases. This represents the first time that a panel of experts thoroughly examined the scientific evidence for risks associated with excess weight and its treatments, and developed recommendations on that basis.

We are continually evolving in our ability to make our educational materials accessible and useful to their intended audiences, and our Web site has provided noteworthy new opportunities. Health care practitioners can now access our Asthma Management Model System, an information management tool designed to facilitate science-based medicine in long-term asthma management. Live Healthier, Live Longer is an interactive site for patients with heart disease. It features a "Virtual Grocery Store," a "Cyber Kitchen," a "Cyber Cafe," a "Fitness Room," and a resource library to assist patients in lowering their blood cholesterol levels. And, as we exploit the new technologies, we continue to employ some time-honored methods for reaching the average American: Our Healthy Heart Handbook for Women is now being promoted on the back of two million cereal boxes, compliments of General Mills.

We are confident that our approach, which is driven both by compelling public health needs and by extraordinary scientific opportunities, will continue to yield similarly gratifying results in the future.

PREPARED STATEMENT OF DR. HAROLD C. SLAVKIN

Mr. Chairman and Members of the Committee: The President in his fiscal year 2000 budget has proposed that the National Institute of Dental and Craniofacial Research (NIDCR) receive $225.7 million, an increase of $5.3 million (or 2.4 percent) over the non-AIDS portion of the fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support proposed for NIDCR is $244.1 million, an increase of $5.7 million over the fiscal year 1999 appropriation. Funds for NIDCR efforts in AIDS research are included within the Office of AIDS Research budget request.

WHAT'S IN A FACE

Several hundred genes of the face, jaws, mouth and teeth have been identified since we met last year, adding to our capacity to address the many diseases and disorders that afflict our Nation. In 1912, Octave Crouzon published the first scientific paper using the term "craniofacial." NIDCR-supported scientists have now identified, sequenced and mapped the gene responsible for Crouzon's syndrome—a point mutation in the fibroblast growth factor receptor 2 gene. Craniofacial encompasses the human face, and reflects a research portfolio that ranges from the prenatal developmental processes that form the human face and dentition, to the pleth-

ora of local and systemic diseases and disorders that attack dental, oral, and craniofacial tissues and structures throughout the lifespan.

BURDEN OF DENTAL AND CRANIOFACIAL DISEASES AND DISORDERS

Dental and craniofacial diseases and disorders are among the most common health problems affecting the people of the United States and around the world. Data on the burden imposed by selected dental and craniofacial diseases and disorders are presented in Poster 2. These conditions range from birth defects like cleft lip and palate , injuries to the head and face, and severe malocclusions, to devastating head and neck cancers. Oral infections such as dental caries, periodontal diseases, and herpes simplex lesions are commonly seen in our population. Orofacial pain is a major component of temporomandibular joint diseases (TMD), Bell's palsy, trigeminal neuralgia and fibromyalgia. In addition, dental and craniofacial conditions are common manifestations of both systemic diseases and treatment of such diseases. These manifestations include oral candidiasis, mucositis, xerostomia (dry mouth) and some forms of periodontal diseases. Many dental and craniofacial health problems have a disproportionately high impact on particular population subgroups.

IDENTIFYING THE BUILDING BLOCKS OF THE HUMAN FACE

Genes that regulate the constellation of biological processes required to form the human face are being discovered. This rapidly expanding knowledge database for the craniofacial genome is becoming the new foundation for molecular medicine and dentistry. Numerous craniofacial syndromes are now diagnosed using gene-based criteria. However, if we acknowledge that the making of the face is not a simple sequential cause-effect problem, we are brought face-to-face with the complexity and nonlinear nature of a developing biological system. Progress on identifying the genetics of human facial syndomes is summarized in Poster 3.

What is exciting and new is our realization that the chemistry of making a human face requires many variable combinations of circuits of biological information. This realization is made possible by recent advances in DNA chips or microarray techniques, some of which have been supported with NIDCR funds. Different kinds of knowledge about faces, including microarray data, are illustrated in Poster 4. Rather than gene-by-gene approaches, microarray provides a strategy to pursue functional genomics by analysis of thousands of genes during a precise stage of craniofacial development within specific cells or tissues. This technology also fosters knowledge discovery, or mining of databases, enhances our capacity to extract potentially useful information and enables the search for global interrelationships. This is referred to as "data mining" and is rapidly advancing through the development of "siftware" software. Meanwhile, investigations into the molecular biology of facial development and numerous craniofacial syndromes are discovering new pieces to the biological puzzle of the design and fabrication of the craniofacial-dental complex. DNA chips are also being used to accelerate the completion of microbial, animal and human genomes. Transgenic animal models such as the zebrafish and the mouse are being used to explore the functional significance of the multiple combinations of genes required for making the human craniofacial complex. Benefits from these discoveries include gene-based diagnostics for hundreds of inherited craniofacial birth defects, and gene-based therapeutics and biomaterials for the repair and regeneration of the tissues of the human face. So—what's in a face?

The panels of Poster 5 highlight the following selected research advances.

IMMUNIZATION FOR DENTAL CARIES

Fluoride and dental sealants are the mainstays of our Nation's dental caries prevention efforts, but much more needs to be done if we are to address the most common childhood disease. Nearly 40 percent of children aged 2–9 years develop caries in primary teeth[1]. Disparities are found in the burden of disease; 25 percent of U.S. children aged 5–17 account for 80 percent of the disease burden in that age group[1].

Tooth decay is an infectious disease caused by Streptococcus mutans; a bacterial microbe that can be transmitted from mother to infant, and that can colonize the surfaces of teeth in early childhood. Research from animal models and preliminary human studies now suggest the feasibility of a molecular-based immunization for dental caries. A current NIDCR-sponsored project is developing plantibodies, antibodies directed against specific Streptococcus mutans antigens, which are produced by genetically engineered plants and then can be eaten to confer passive immunity.

[1] Kaste LM, Selwitz RH, Oldakowski RJ, Brunelle JA, Winn DM, Brown LJ: Journal of Dental Research 75: 631–641, 1996.

The immunoglobulin A (IgA) antibodies directed against the Streptococcus mutans antigens have been found effective in preventing recolonization on the enamel tooth surface by Streptococcus mutans. To date, animals and humans fed plantibodies have shown no toxic side effects. A phase I clinical trial of plantibodies in children "at risk" for rampant dental caries is under way.

NIDCR MICROBIAL GENOMICS PROJECTS

Understanding how microbes function in complex ecosystems is a critical step towards controlling the numerous infections they cause. One of these microbes, Candida albicans, is a yeast that lives on the mucous membranes of the mouth and under certain conditions creates a life-threatening systemic infection. Candida causes a variety of infections ranging from mucosal infections in generally healthy persons to life-threatening systemic infections in individuals with impaired or compromised immunity. Candidiasis is one of the earliest and most common opportunistic infections to occur in the oral cavity of HIV-infected individuals. Because of the few safe and effective antifungal drugs, along with what appears to be increased drug resistance to the most common treatments for candidiasis, it is important to rapidly complete the Candida genome and then use this knowledge database for functional genomic studies with microarray technology to identify and develop innovative and effective new drugs.

The completion of the Candida genome is expected by the end of this calendar year. The anticipated database will contain genes related to yeast reproduction, drug resistance, and pathogenicity. We also anticipate the completion of four other microbial genome studies designed to understand the molecular biology of important opportunistic oral/dental pathogens including Porphryomonas gingivalis, Streptococcus mutans, Actinobacillus actinomycetemcomitans and Treponema denticola.

ADVANCES IN UNDERSTANDING ORAL CANCER

Recent findings from NIDCR-sponsored projects are addressing basic, translational and clinical research questions. How do oral epithelial cells become malignant? How can we detect precancerous cells? How can we develop "smarter" therapies without toxic side effects? How can we prevent or reduce the burden of oral cancer? Three different tumor suppression mechanisms have recently been discovered: DOC–1, PTEN, and E-cadherin. DOC–1 is a new tumor suppressor gene and the protein it encodes is expressed in normal human tissues including oral keratinocytes. However, DOC–1 protein is not detectable in human oral cancers. This discovery suggests that a faulty DOC–1 gene may contribute to the development of oral cancer. PTEN is another tumor suppressor gene discovered to be defective in many advanced human cancers, including those in the head and neck region. NIDCR scientists have suggested how loss of PTEN may lead to cancer progression. E-cadherin is a cell-surface membrane protein that mediates cell to cell adhesion. E-cadherin was discovered to regulate the growth and survival of oral squamous cancer cells. Importantly, anti-E-cadherin antibodies inhibit the growth of oral cancer cells. Understanding the genetic basis for cancers afflicting the head and neck provides the opportunity to develop new diagnostics and preventive strategies.

NEW ERA OF THERAPEUTICS

NIDCR scientists are in the forefront of developing the next generation of gene-based therapeutics and biomaterials. The advances have the potential to address a wide range of oral, dental, craniofacial and systemic health problems. Poster 6 summarizes selected promising research areas. Salivary glands. I am pleased to report that gene therapy to restore salivary gland function was successful in an animal model, and work on the development of an artificial salivary gland to produce saliva is in progress. Salivary gland dysfunctions are problematic for patients with Sjogren's syndrome, cystic fibrosis, and tissue damage resulting from radiation therapy. Bone and joint tissues. A new mouse model of osteoporosis has been developed, and results from work on gene therapy in arthritic rats are promising. Research on bone morphogenetic proteins (BMPs) and cartilage-derived morphogenetic proteins (CDMPs) is directed to therapeutic regeneration of these tissues. Disorders of bone and joint tissue pose a large national health problem that will grow larger with the aging of the population. Tooth enamel. Our capacity to design and fabricate an enamel bioceramic is progressing. Five tooth enamel genes have been identified, sequenced and mapped to chromosomes and their protein products are now being used in new strategies for enamel repair and regeneration. Pain. We are continuing to learn how to stimulate the body's natural "therapeutics." An animal model of gene therapy to stimulate production of beta-endorphins may be the basis of a future treatment for chronic pain conditions. Wound healing. A variety of new mol-

ecules have been discovered that may enhance soft as well as hard tissue wound healing. Sometimes unexpected discoveries in one field open the door to a new line of research in a different field. Secretory leukocyte protease inhibitor (SLPI), a component of saliva known to inhibit HIV, is now being explored as a potential therapy for defective wound healing.

The activities of the NIDCR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

This is an exciting time for NIDCR and for the NIH. We are poised to capitalize on the many significant advances in fundamental science, especially in genetics, structural biology, molecular, cellular and developmental biology, the neurosciences, computer science and innovations in imaging technologies. Our Nation's investment in biomedical research has paid enormous dividends and will continue to do so well into the next century.

PREPARED STATEMENT OF DR. PHILLIP GORDEN

Mr. Chairman and Members of the Committee: I am pleased to testify on behalf of the research programs, progress and opportunities of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Our institute has responsibility for the national biomedical research effort to combat some of the most important, chronic diseases in this country, including diabetes, endocrine and metabolic diseases; digestive diseases and nutritional disorders; and diseases of the kidney, urologic tract and blood. These diseases inflict tremendous suffering and health care costs on the American people because they are life-long, debilitating, and often relentless. The President in his fiscal year 2000 budget proposed that the NIDDK receive $1,002.7 million, an increase of $23.4 million (2.4 percent) over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support proposed for NIDDK is $1,021.1 million, an increase of $23.9 million over the fiscal year 1999 appropriation. Funds for NIDDK efforts in AIDS research are included within the Office of AIDS Research budget request.

The activities of the NIDDK are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

As the Nation turns the page to the 21st century, the NIDDK will be celebrating its 50th anniversary. Thus, it is a time for both reflecting upon the Institute's accomplishments and looking forward to the promise of future research advances. In this vein I would like to strike two important themes. The first is to emphasize our clinical advances and their special relevance to the treatment and prevention of disease. The second is to underscore the vital basic science discoveries that create the technology that drives these advances. Both aspects of research are critically important and must be strongly supported and nurtured.

CLINICAL ADVANCES AND THEIR SPECIAL RELEVANCE TO THE TREATMENT AND PREVENTION OF DISEASE

A major multicenter, large-scale clinical trial in patients with type 2 diabetes has clearly demonstrated the efficacy of good blood sugar control in ameliorating the microvascular eye, kidney, and nerve complications. This study is an important confirmation of the NIDDK's major Diabetes Control and Complications Trial, which demonstrated similar benefits in type 1 diabetes. In addition, the recently completed type 2 trial demonstrated that good blood pressure control produced a major benefit in decreasing macro vascular events such as stroke. These findings give new emphasis to the value of early treatment in type 2 diabetes. They also reinforce the impor-

tance of our Diabetes Prevention Program, a major clinical trial for which recruitment is almost complete. This trial focuses on adding a prevention strategy to existing therapeutic approaches. It is especially addressed to our minority populations who are disproportionately affected by type 2 diabetes.

Previously, we considered end stage renal disease to be an inexorable consequence of severe kidney complications of diabetes. Recent studies now show that the type of long-term glucose control that can be accomplished by pancreas transplantation can actually lead, over a long period of time, to a reversal of these complications. These remarkable findings have revolutionized our clinical thinking about the progression of the kidney complications of diabetes and have reinforced the importance of glucose control as demonstrated in other studies.

Advances in producing immune tolerance to enable transplant recipients to accept and retain donated organs and tissue have given new emphasis to the field of transplantation and its role in the treatment of diabetes and end-stage renal disease. To capitalize on these achievements, we are investing in a new intramural effort focusing on both kidney transplantation and pancreatic islet cell transplantation. We are also pursuing a major multi-institution initiative in islet cell transplantation. These endeavors are an excellent example of how NIDDK program development is shaped by emerging scientific opportunities that are created by technology development.

In hepatitis C, the NIDDK intramural program carried out the initial studies demonstrating the therapeutic efficacy of alpha interferon. This advance was possible because of fundamental studies showing that this type of agent could inhibit viral replication and because of biotechnology advances permitting the manufacture of such compounds. These studies spurred further drug development and a more profound understanding of the nature of the hepatitis C virus. As a result, we now have a new combination therapy using alpha interferon and another anti-viral agent, ribavirin. Used together, these drugs lead to long-term remission of hepatitis C infection in up to 40 percent of individuals. Furthermore, using knowledge about the various subtypes of viruses that lead to this disease, we can tailor this therapeutic strategy more effectively to individual patients. These developments constitute a significant therapeutic advance in a disease that affects over four million Americans and is the leading cause of end-stage liver disease.

For the debilitating bone disease, osteoporosis, we have introduced a number of therapeutic strategies founded on basic research and made possible by the technology revolution. During the past year, researchers have demonstrated that parathyroid hormone, an important regulator of bone metabolism, has an important beneficial effect in increasing bone density. This research adds another impressive clinical tool to the treatment and understanding of osteoporosis.

IMPORTANT BASIC DISCOVERIES CREATE TECHNOLOGIES THAT DRIVE CLINICAL ADVANCES

In obesity research, the initial discovery of the major energy regulator, leptin, in a mouse model of obesity led to the discovery in rodents of multiple gene mutations, which control critical aspects of both eating and energy regulation. These findings have now led to the discovery of at least five different genetic defects in humans that lead to obesity. These important research advances have relevance not only to our understanding of obesity per se, but also to the inter-relationship of obesity and diabetes.

While leptin itself may not prove to be a major therapy for obesity, it has clearly led us in directions that are likely to produce major therapeutic progress. In addition, these discoveries have infused our obesity research portfolio with innovative ideas for further understanding of the molecular basis of obesity. This research, in turn, is expected to reveal new therapeutic targets. For example, we are making a substantial investment in a multi-center clinical trial to demonstrate the health benefits of long-term, voluntary weight loss. This clinical trial will be conducted in obese patients with type 2 diabetes. In this way, we will test both lifestyle and drug strategies highly relevant to both obesity and diabetes.

In addition, our major investment in genetic and functional genomics research has led to the discovery of at least six separate genetic defects in rare forms of type 2 diabetes. These studies have stimulated collaborative research to penetrate the complexity of genetic abnormalities in both type 1 and type 2 diabetes. Expansion of these studies is now under way, with an emphasis on the kidney complications of diabetes. Thus, we are now making a major commitment to a large-scale study of the genetics of diabetes per se and the genetic susceptibility to diabetic renal disease.

Ground-breaking discoveries of genes that cause cystic fibrosis, polycystic kidney disease, and hemochromatosis are leading to investments to an understanding of the

functions of these genes. These discoveries give us the opportunity to develop screening strategies for early intervention in the iron-overload syndromes, such as hemochromatosis. They likewise provide promising opportunities to discover new therapeutic strategies for other liver diseases, Cooley's anemia, and neurodegenerative diseases.

Our endocrine program has provided the basis for understanding the development of designer-type drugs, such as estrogen compounds. Technology has enabled researchers to devise novel drugs, which have specific beneficial effects on certain tissues, such as bone, and do not carry the adverse effects on breast and uterus seen in the more classic estrogen preparations. We are now beginning to understand the basis for this type of tissue specificity, which affords us the opportunity to use knowledge derived from basic research to develop clinical approaches to endocrine-responsive cancers, such as prostate and breast cancer.

INFRASTRUCTURE DEVELOPMENT

To sustain and enhance these clinical advances, and the fundamental science that drives the technologic applications from which they flow, it is imperative that we maintain a strong infrastructure of support. The first and perhaps most important component of the research enterprise is "human infrastructure." We are renewing our efforts to strengthen research training and career development to ensure that we have the cadre of talented scientists needed for the 21st century. We are encouraging and participating in the NIH-wide effort to bolster the recruitment and training of modern-day clinical investigators. We are also making a major investment in biotechnology centers in an attempt to use the most modern approaches to both gene discovery and its application to gene function and to therapeutic advancement. Complementing these activities are NIDDK's participation in trans-NIH infrastructure initiatives such as the zebrafish and mouse genome efforts to provide critical research resources to investigators.

Other examples abound demonstrating that an insight gained from undifferentiated, technology-based laboratory research is often transformed into a clinical stride forward, with widespread application to various disease processes. For instance, the generation of new knowledge about the physiology of erectile function has helped pave the way to the development of agents such as Viagra. Another example is the use of modern technology to develop antibody treatment for refractory Crohn's disease, and to gain insights into processes that are implicated in areas of women's urologic health such as interstitial cystitis and incontinence.

Genetic engineering techniques enabled the production of synthetic human erythropoietin, a hormone useful in treating the anemia of end-stage renal disease and other conditions. Most recent studies have shown that a modified form of erythropoietin, linking two molecules together, can create a more potent drug with a longer half-life. With this new approach, it is possible to reduce the cost of this treatment while maintaining its efficacy.

We are also able to conceptualize totally new and promising strategies based on a more profound understanding of underlying disease processes. Because of clinical studies made possible by high-technology basic research, we are developing new prevention strategies to fight disease. For example, both animal and human studies of type 1 diabetes demonstrate a shift from beneficial to destructive inflammatory mediators of the immune system called cytokines. With this knowledge, we are formulating innovative, prevention-oriented approaches, including the development of special reagents aimed at interdicting this process.

Modern technology lets us visualize disease at the molecular level; measure and assess biologic events in amazingly precise ways; develop therapies that are site-specific; and test hypotheses in sophisticated model systems. The application of these technologies to basic research questions in the laboratory is often the critical first step to combating disease.

At the threshold to the 21st century, we are on the brink of enormous clinical progress. In some diseases areas, we sense extraordinary research momentum propelling us forward toward major medical advances. In other areas, we are still at an "interface" between an important, clinically-relevant finding that augurs eventual application to the practice of medicine. In still others, much more basic research needs to be done before clinical insights can surface. In every field, however, the technology revolution is moving basic research forward into the clinical arena at an unprecedented and truly exciting pace.

PREPARED STATEMENT OF DR. GERALD FISCHBACH

Mr. Chairman and Committee Members: Mr. Chairman and members of the Committee. I am pleased to present the President's non-AIDS budget request for the NINDS for fiscal year 2000, a sum of $890,816,000, which reflects an increase of $20,842,000 over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support requested for NINDS is $920,970,000, an increase of $21,563,000 over the fiscal year 1999 appropriation. Funds for the NINDS efforts in AIDS research are included within the Office of AIDS Research budget request.

Thank you for the opportunity to appear before this Committee. I am Gerald Fischbach. I assumed this challenging job with great enthusiasm seven months ago, after 30 years of research, teaching, and academic administration. My enthusiasm is based on the rapid advance of neuroscience research at all levels of analysis from molecules to mind, and on the desperate need to apply those new discoveries to the devastating disorders of the nervous system. Scientific opportunities are abundant, the need for preventing and treating nervous system diseases has never been greater, and the confidence of the public in biomedical research has never been stronger.

Perhaps because it is so complex, the nervous system is also very vulnerable. The immature nervous system is subject to muscular dystrophies, spinal muscular atrophy, autism, hereditary ataxias, cerebral palsy, and many other developmental disorders. Among the common maladies in the mature nervous system are stroke, trauma, multiple sclerosis, brain tumors, and chronic degenerative disorders such as amyotrophic lateral sclerosis, Parkinson's, and Alzheimer's disease. Nervous system diseases rob people of their ability to feel, to move, to remember, and, ultimately of their identity. They place unspeakable burdens on families as well as patients.

The mission of NINDS is to reduce the burden of neurological disorders by conducting and supporting research on the normal and diseased nervous system. To move toward achieving this mission, we have initiated a new, intensive planning process. More than 100 leading neuroscientists, drawn from the extramural community and the intramural program, joined our staff and members of the lay public to suggest areas of opportunity in the coming two to three years. This is the first step in an ongoing effort to set priorities in an era of changing needs and opportunities. An overview of our current highest priorities can be stated simply. We must:

—attack neurodegenerative disorders over the entire life span.

—promote research on development of the immature nervous system and on regeneration in the mature nervous system.

—gain a greater understanding of synapses and circuits in the brain to develop more effective therapies for disorders such as epilepsy and chronic pain and to understand brain mechanisms underlying normal cognition and memory loss.

—understand the crucial supporting roles of glia and other non-neuronal cells in the normal brain and in disorders like brain tumors and multiple sclerosis.

—provide infrastructure support for the national neuroscience enterprise, promote the distribution of crucial and currently scarce resources, and expand clinical trials.

The anatomical, physiological, and biochemical complexity of neural circuits challenges the ingenuity of scientists working on the brain. Fortunately, useful simplifications have emerged that bring order to observations previously thought to be unrelated and bring basic neuroscience closer to clinical application. For example, nerve cells in all species use the same mechanisms to generate signals. Likewise, similar molecules determine the birth, maturation and death of nerve cells in humans, monkeys, mice, flies, and worms. Lower organisms can, therefore, help elucidate mechanisms of human disease. Another simplification is that the same processes influence nerve cell death in seemingly different conditions. In both acute and chronic disorders many cells die by activating intrinsic "cell suicide" programs. If we can stop cell death in one condition, then the insights gained will, very likely, apply to other disorders as well.

Molecular genetics is a unifying force in all biology. Because more than half of our genes are expressed in the brain, the potential contribution of genetics to understanding nervous system disorders is extraordinary. But I also want to stress that patterns of electrical activity, or, to use another word, "experiences," play an enormously important role in shaping brain circuits. The interplay between genes and the environment reveals that circuits in the mature brain can change to a remarkable degree. This "plasticity" is the best hope for recovery of function following acute insults or during chronic disease. Genetically engineered neurotrophic factors, implantation of stem cells, and novel behavioral paradigms are therefore likely future therapies.

PARKINSON'S AND OTHER NEURODEGENERATIVE DISORDERS

Parkinson's disease is marked by a characteristic "resting" tremor, a progressive slowing of voluntary movement, muscular rigidity, postural instability, and, in some cases, progressive dementia. This is a complex disorder, but there is a sense of renewed optimism with new surgical and medical therapies emerging. We are committed to supporting a vigorous and expanding program of research in Parkinson's disease and to moving toward full implementation of the Morris K. Udall Parkinson's Disease Research Act.

NINDS now supports five clinical trials in Parkinson's disease, including implantation of cells that produce and release dopamine, a chemical neurotransmitter essential for the normal function of circuits that regulate voluntary movements. Another approach aims to surgically reduce the brain's overactive inhibition of movement. Other trials seek to slow the loss of dopamine containing neurons with drugs that minimize oxidative damage. This is a good beginning, but additional approaches are needed.

In no area of medicine is the potential for harnessing human stem cells greater than in diseases of the nervous system. This year brought significant progress toward the development of neural stem cell therapies with encouraging results in animal models of Parkinson's disease. Scientific and ethical considerations must be addressed, but these early successes bring us closer to early trials in Parkinson's disease and other disorders.

Surgical ablation of the globus pallidus is designed to restore the balance between brain circuits that initiate movement and other circuits that inhibit movement. A new study suggests that unilateral pallidotomy may be effective when medical therapy has failed. Patients are now being followed to see how long the benefits last. This success clearly shows that analysis of circuits as well as analysis of molecules and individual cells is crucial for progress in treating nervous system diseases.

Another promising treatment for Parkinson's disease is chronic electrical stimulation delivered through electrodes implanted deep within the brain's movement control centers. The Food and Drug Administration has approved deep brain stimulation (DBS) for treatment of certain types of tremor. New evidence, mostly from Europe, suggests that DBS delivered to other brain movement centers can relieve more debilitating symptoms of Parkinson's disease, such as muscular rigidity and paucity of movement. There are tantalizing hints that DBS may even slow the progression of the disease. DBS emphasizes the importance of electrical activity on brain cells, and DBS may be useful for many other nervous system disorders.

On other fronts, several labs are exploring new neurotrophic factors that have potent actions on dopamine nerve cells and novel agents that interrupt the enzyme cascade that leads to nerve cell suicide. Studies of inherited forms of Parkinson's disease, Alzheimer's disease, and ALS are also leading to crucial clues about the non-inherited "sporadic" cases. Although most cases of these diseases are not inherited, the same pathways are probably involved. Findings in each neurodegenerative disease are informing studies of the others.

SPINAL CORD INJURY

Severed nerve cells in the central nervous system can be coaxed to regrow and reach toward their abandoned targets. However, the growth of axons (nerve fibers) is limited by inhibitory factors. After regrowth, the next challenge is to reconstruct the precise connections required for coordinated movement. In the spinal cord we now know that the disconnected circuits below the lesion remain intact. We plan a major effort to uncover factors that will facilitate regrowth of dormant nerve cell axons, and that will guide their "recognition" of correct target cells to reestablish control of local circuits in the spinal cord that are responsible for locomotion and other coordinated movements.

To repair the injured adult spinal cord, reactivating the mechanisms that wire up the nervous system during early development will almost certainly be essential. We plan to develop novel funding mechanisms that bridge the gap that now seems to separate developmental neurobiologists from those interested in regeneration and rehabilitation. This effort may serve as a model for the back-and-forth interplay between basic and clinical studies that is needed as we move from treatment of symptoms toward cures.

EPILEPSY

Seizures are caused by "electrical storms" in the brain, during which groups of nerve cells fire electrical impulses at a high rate and in synchrony. Here too genetics, circuits, electrical activity, and mechanisms of neuronal plasticity are emerging

as unifying themes. In the coming year we will emphasize the opportunities that studying the genetics of affected families are uncovering for understanding and treating epilepsy.

Defects in single genes cause more than 100 forms of epilepsy. In many cases, the "disease genes" encode proteins that generate the electrical impulses that carry information along and between nerve cells. These crucial proteins are the molecular switches that regulate the orderly flow of information in the nervous system. Each presents a target for developing new and better drugs. In the past year, scientists discovered a new class of mutations that lead to epilepsy. Genes have been discovered that influence the migration of neurons from where they are "born" in the embryonic brain to their proper places in the adult brain. When mutated, these genes cause global, catastrophic brain malformations or more subtle defects involving only small groups of neurons. The more subtle defects, revealed by new, high resolution brain imaging, are far more common than previously suspected, and may explain many seizures previously categorized as of unknown cause. As is the case for many inherited diseases, more than one gene may be involved in susceptibility to seizures. Epilepsy is an excellent place to begin a analysis of multigenic disorders. We are optimistic that the time is right to eliminate epilepsy rather than simply minimize the symptoms.

STROKE

A new study suggested that more than 700,000 strokes occur each year in the United States, far more than previously suspected. Still, most people, especially the elderly who are at high risk, cannot identify the symptoms of stroke. These facts are particularly disturbing because NINDS t-PA clinical trials have shown that treatment within the first three hours of onset of a "brain attack" can improve the outcome. These treatments are costly, but, in the long run, they save money by reducing long-term disability. NINDS has mounted a large public education program geared at patients and physicians to improve early detection and treatment. We continue to search for new approaches for preventing stroke and for minimizing, or reversing, the damage that does occur.

CLINICAL RESEARCH

Recognizing the opportunities cited above and many others, we have created a new division of Clinical Trials and Experimental Therapeutics within the NINDS extramural program to promote and guide our efforts. A critical issue in clinical research is the need for surrogate markers and early diagnostics. In neurodegernative disorders many nerve cells are already lost before the first obvious signs of disease are manifest. We must diagnose degenerative diseases earlier in their course to develop effective interventions. Expanded clinical research also depends on training a new and diverse generation of clinical investigators.

Our goal is clear. We must cure or prevent all neurodegenerative disorders, acute and chronic, that affect infants, children, adults, and the elderly. We must reduce the devastating damage caused by disorders such as epilepsy and multiple sclerosis, not just mask the symptoms. We must learn to repair the damaged nervous system, not just halt degeneration. We must apply insights of modern brain science to the problems of mental life, from the emotional void of autism to the cognitive decline of aging. At the beginning of my career these goals were unattainable. Now they are within our reach.

The activities of the NINDS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF ANTHONY S. FAUCI, M.D.

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Allergy and Infectious Diseases (NIAID) for Fiscal Year 2000. The President proposes that the NIAID receive $789.2 million, an increase of 2.4 percent for NIAID non-AIDS research activities. Including

the estimated allocation for AIDS research activities, total support proposed for the NIAID is $1.6 million, an increase of 2.4 percent over the comparable fiscal year 1999 appropriation. Funds for NIAID AIDS research efforts are included in the Office of AIDS Research budget request.

DOMESTIC AND GLOBAL HEALTH: REDUCING THE BURDEN OF INFECTIOUS DISEASES

A central goal of NIAID is to reduce the burden of infectious diseases, which remain the leading cause of death worldwide and the third leading cause of death in the United States. This is a daunting challenge since newly recognized diseases such as AIDS are superimposed on old foes such as malaria and tuberculosis, which continue to exact a huge toll. In today's world, the enormous volume of international travel and trade has largely erased the distinction between domestic and global health problems. Americans are vulnerable to infectious diseases that emerge anywhere in the world: a virulent strain of influenza virus, for example, could reach our shores in less than a day from virtually anywhere on the globe. A bioterrorist's attack could impact wide geographical areas; microbes do not stop at borders.

Further compounding the problem of infectious diseases is the widespread emergence of drug-resistant pathogens. For example, the World Health Organization estimates that strains of the tuberculosis bacterium resistant to one or more drugs have infected up to 50 million people worldwide. Because of drug resistance, nearly 10 percent of invasive pneumococcal infections in the United States 1997 were untreatable with the three leading classes of antibiotics. Many other common diseases are increasingly resistant to standard drugs, including infections with common bacteria such as staphylococci, sexually transmitted diseases, and food-borne illnesses.

Against this backdrop, the Institute's multi-faceted efforts in understanding disease-causing microbes and how they develop drug resistance, delineating the human immune response to pathogens, and developing new diagnostics, interventions and vaccines, are critical to our ability to address current microbial threats, as well as those that will inevitably emerge in the future.

HIV/AIDS IN THE UNITED STATES

Considerable progress has been made against one of the world's leading infectious causes of death, the human immunodeficiency virus (HIV), the cause of AIDS. In the United States, the number of new AIDS cases and AIDS-related deaths has dropped dramatically. Among people aged 25 to 44, AIDS is now the fifth leading cause of death; just three years ago it was the leading cause of death in this age group. The recent decline in HIV related mortality in the United States is due to several factors, particularly the increased use of potent combinations of antiHIV drugs. The development of 15 licensed antiretroviral drugs has been facilitated by NIAID-supported basic research on HIV and the immune system. In addition, many of the pivotal clinical trials of these medications have been conducted within the NIAID network of clinical trials programs.

Despite the improved prognosis for HIV infected individuals in the United States and other western countries, it is essential that we not become complacent with regard to the HIV/AIDS epidemic. The rate of new HIV infections in the United States approximately 40,000 per year continues at an unacceptably high level. In addition, many HIVinfected individuals have not responded adequately to currently available antiHIV drugs, cannot tolerate their toxicities and side effects, or have difficulty adhering to complex dosing schedules.

These realities underscore the importance of NIAID's ongoing research into learning more about the HIV disease process and developing the next generation of antiretroviral therapies, including those aimed at targets in the viral replication cycle not addressed by current therapies.

AIDS VACCINE AND PREVENTION RESEARCH

Elsewhere in the world, the HIV epidemic continues to accelerate, notably in sub-Saharan Africa, Asia, the Indian sub-continent, and certain countries in the former Soviet Union. The expansion of the epidemic in the developing world, where expensive anti-HIV drugs are beyond reach of all but the privileged few, underscores the urgent need for a safe and effective HIV vaccine. A sustained commitment to basic and applied HIV vaccine research is critical, as is the further development of topical microbicides and other approaches to HIV prevention.

As part of the NIAID effort in HIV vaccine development, the Institute has awarded more than 100 grants in a special program that fosters innovative research on HIV vaccines. Many novel approaches to an HIV vaccine are now being pursued, including vectored vaccines, which employ harmless viruses engineered to carry genes encoding one or more HIV proteins. Phase I and Phase II studies of this ap-

proach in the United States have yielded promising results. The Institute also is a partner in the NIH Vaccine Research Center (VRC), a new program involving NIH scientists with expertise in immunology, virology and vaccine development.

GENOMIC SEQUENCING

Genomic sequencing technology has revolutionized medical research and is intimately linked to the Institute's mission. Although this technology is most often associated with the Human Genome Project, it is less widely known that numerous projects are underway to sequence the genomes of disease-causing microbes. These initiatives promise to speed vaccine and drug development, as well as to facilitate studies of disease pathogenesis and drug resistance. In 1998 alone, NIAID-supported researchers reported the complete genomic sequence of three important pathogens: the agents of chlamydia, syphilis and tuberculosis, as well as the sequence of one of the chromosomes of the malaria parasite Plasmodium falciparum. Significantly, no good vaccine exists for these four diseases. The new genomic sequence data promises to provide important insights regarding the components of these organisms that might be incorporated into candidate vaccines.

NIAID MALARIA RESEARCH

Malaria is one of the most devastating emerging and re-emerging diseases. It claims 1.5 to 2.7 million lives each year in tropical and subtropical regions of the world, according to the World Health Organization (WHO). Every 30 seconds, a child dies of malaria. As a partner in the Multilateral Initiative on Malaria (MIM), NIH is facing the challenges of malaria with laboratory, fieldbased and clinical research efforts within the NIAID intramural research program in Bethesda, Md., at grantee institutions elsewhere in the United States, and in collaboration with foreign colleagues in Africa, Asia, South America, and the Pacific region. In this endeavor, we and our colleagues in the MIM have an important new ally, World Health Director General Dr. Gro Harlem Brundtland, who recently launched the ambitious "Roll-Back Malaria" program.

VACCINE DEVELOPMENT

The importance of vaccines in the control of infectious diseases cannot be overstated—they provide safe, cost effective and efficient means of preventing illness, disability and death from these diseases. Indeed, vaccines are the only human interventions that have actually eradicated diseases: the last case of smallpox anywhere on earth occurred in 1977, and polio has been eradicated from the western hemisphere, the western Pacific region, and virtually all of Europe. The complete elimination of polio, and perhaps other vaccine-preventable diseases, is within our grasp.

Each of the core scientific disciplines of NIAID—immunology, microbiology and infectious diseases—contributes to the development of new vaccines. Progress in basic research as well as technical advances have created opportunities for improving the safety and efficacy of existing vaccines as well as for developing vaccines for diseases for which no vaccines are currently available.

ROTAVIRUS VACCINE LICENSED

NIAID intramural research spanning 25 years recently culminated in the licensure of a vaccine against rotavirus, a leading cause of life-threatening childhood diarrhea. Widespread use of the rotavirus vaccine promises to reduce the 160,000 emergency room visits and 50,000 hospitalizations necessitated by rotavirus infections each year in this country, according to the Centers for Disease Control and Prevention (CDC). Global use of the vaccine could significantly lessen the impact rotavirus diarrhea, which affects 130 million infants and children each year, resulting in more than 870,000 deaths, according to the WHO.

CONJUGATED HIB VACCINES: A CONTINUING SUCCESS STORY

Another notable success in vaccinology is the development of conjugated vaccines to protect children under two years of age from Haemophilus influenzae type B (Hib), a microbe which can cause meningitis, deafness and mortality in young children. The success of Hib conjugate vaccines has been extraordinary: more than 35 countries have followed the lead of the United States and adopted these vaccines into their immunization programs, cutting the incidence of invasive Hib disease to negligible levels wherever the vaccine has been used. In the United States only 258 cases of invasive Hib disease among children younger than 5 years were reported in 1997, a 97-percent reduction from 1987. The Children's Vaccine Initiative has estimated that conjugated Hib vaccines, if used routinely and in the same proportion

of+ children as other childhood vaccines, could prevent about 70 percent of the estimated 400,000 annual Hib-related deaths worldwide.

TUBERCULOSIS VACCINE RESEARCH

Last year, TB claimed the lives of nearly 3 million people, more than any other single infectious disease, according to the WHO. Clearly, an effective TB vaccine is needed, as well as new therapeutics. The Institute is working to develop a TB vaccine with a twotiered approach: basic research into the pathogenesis of the disease and the host immune response to infection with the TB bacterium; and applied research into vaccine candidates. Several experimental vaccine approaches appear promising, and the NIAID recently joined forces with public and private sector health agencies to formulate a "blueprint" to speed TB vaccine development.

RESPONDING TO THE THREAT OF BIOTERRORISM

Recent terrorist attacks such as those in New York, Oklahoma City and Tokyo, the uncovering of advanced biological weapons in Iraq and the former Soviet Union, and other events have reinforced the urgent need to prepare for possible biological attack. As recently articulated by President Clinton, the NIH and NIAID have a central role is countering the threat of bioterrorism. The Institute has developed a bioterrorism research plan that consists of basic research into the pathogenesis and genetics of organisms which might be used in bioweapons, as well as the development of techniques for rapid identification of natural and bioengineered microbes, new therapies against these microbes, and vaccines to prevent infections with these agents. Our efforts are focused on four organisms known to be potential agents of bioterrorism: smallpox, anthrax, tularemia and plague. Important initiatives include collaborative research with the Department of Defense to identify antiviral drugs with the potential to treat or cure smallpox infections, and efforts to develop an improved anthrax vaccine.

NEW APPROACHES TO IMMUNOLOGIC DISEASES

The immune response is central to human health. However, the immune system can go awry, as in the case of autoimmune diseases, in which a person's immune system targets their own organs or tissue. Collectively, autoimmune diseases afflict several million Americans, an estimated five percent of the population. The human and financial burden of these diseases is immense. To address the problem of autoimmune diseases, a trans-NIH working group has develop cross-cutting initiatives to address various aspects of autoimmunity, including the roles of environmental, infectious and genetic factors in these diseases, as well as innovative therapies such as stem cell and islet cell transplantation. An important area of emphasis is the induction of tolerance. By blocking only those components of the immune system that attack healthy tissues, it may be possible to treat autoimmune diseases while avoiding immunosuppressive drugs that dampen not only the deleterious immune response, but also responses needed to protect a person from infections and cancers.

In addition to its applications in autoimmunity, tolerance induction holds extraordinary promise in transplantation biology. Researchers have shown that novel approaches to tolerance induction allow long-term, rejection free survival of transplanted kidneys and insulin-producing islet cells in monkeys, without immunosuppressive drugs. A comprehensive NIAID tolerance research plan has been developed to identify research gaps and opportunities, and to outline areas of future basic and clinical research in autoimmunity, transplantation, asthma and allergic diseases.

CONCLUSION

The activities of NIAID are covered within the NIHwide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

The Institute is poised to take advantage of unprecedented scientific opportunities in immunology, microbiology and infectious diseases. With a strong research base, talented and committed investigators, and the availability of powerful new research

tools, NIAID looks to the new millennium with confidence that new advances that will have significant impact on the health of our nation and the world are within our grasp.

PREPARED STATEMENT OF DR. MARVIN CASSMAN

Mr. Chairman and Members of the Committee: The President in his fiscal year 2000 budget has proposed that the National Institute of General Medical Sciences (NIGMS) receive $1.194 billion, an increase of $28 million over the comparable fiscal year 1999 appropriations. Including the estimated allocation for AIDS, the total support proposed for NIGMS is $1.227 billion, an increase of $29 million over the fiscal year 1999 appropriation. Funds for NIGMS efforts in AIDS research are included within the Office of AIDS Research budget request.

I am pleased to present to you the programs of the National Institute of General Medical Sciences (NIGMS). The NIGMS mission is to support basic biomedical research that is not targeted to specific diseases, but that increases understanding of life processes and lays the foundation for advances in disease diagnosis, treatment, and prevention. The Institute also has a major role in training the next generation of scientists. As part of this effort, we attempt to ensure that biomedical research has access to the broadest possible intellectual resources in our society, through programs that provide research and training support for underrepresented minorities.

A LOOK BACK

I would like to begin by describing two important recent research advances that illustrate the long-term nature of the research we support, the way in which it often draws from observations made in a number of different organisms, and the speed with which many of these fundamental studies become relevant to the human condition.

The first advance involves an essential component of the cell, called the microtubule. Microtubules are long, stiff structures that extend through the cell [Figure 1] and are involved in such key functions as cell division and the movement of material within the cell. An understanding of the structure and function of the microtubule has been a major scientific goal for several decades.

Recently, investigators supported by NIGMS have determined the three-dimensional structure of the units that make up the microtubules, called tubulin. Of particular interest is the fact that the anti-cancer drug, Taxol, acts by binding to tubulin. The location of the Taxol on the tubulin molecule is clearly visible in this structure. The identification of the binding site for Taxol will help in developing new anti-cancer drugs.

This very important structure was determined by a relatively novel technique. Since tubulin spontaneously aggregates into very large sheets, the usual methods for detailed structure determination, X-ray diffraction and nuclear magnetic resonance, could not be used. Instead, the researchers used a powerful variant of electron microscopy, which is increasingly being applied to the analysis of large, complex structures. Development of this tool has been supported by NIGMS for more than two decades, and is now coming to fruition in this and other research areas.

A second major research advance is in the understanding of one of the most pervasive and, until recently, least understood aspects of biological systems, the circadian rhythm. This pattern of activity, with a periodicity of about 24 hours, appears to be present everywhere one looks, from plants to yeast to fruit flies to humans. Disruption of the biological clock is most apparent in the sleep disorders that accompany jet lag, but the clock almost certainly plays a fundamental role in the normal physiology of living organisms. Although studies on the molecular basis of circadian rhythms have been underway for at least 30 years, the last 18 months have yielded an explosion of information on the way that cellular clocks operate. The general mechanism looks quite simple at this point, although the simplicity is undoubtedly deceiving, and much yet remains to be learned [Figure 2]. This simple model shows a feedback loop, where a pair of proteins (the PAS proteins) stimulates the synthesis of the clock proteins. As these increase in concentration, they prevent the PAS proteins from promoting their synthesis, and the concentration of the clock proteins drops. A new cycle is then initiated. The timing of this cycle of synthesis, inhibition, and renewal determines the period of the cellular clock.

It is striking that very similar proteins exist in all the organisms studied, from yeast to mammals. This similarly also extends to one of the mechanisms by which the cycle is triggered, that is, the response to light. Recently, three NIGMS-supported research teams have identified the way the cells respond to light to modulate

this cycle. Again, it is striking that the photoreceptor is the same in the plant model, in fruit flies, and in mice.

A LOOK AHEAD

I would like to spend the rest of my time dealing not with the past, but with the future. However, there are certain common features that have led to the successes of the past, and that we will continue to emphasize in the future. The two examples I just gave demonstrate many of these features. The application of novel technologies, the use of detailed structural information to understand the ways that drugs work, the use of model systems to understand fundamental biological processes, and the application of genomic information to identify proteins with common functions in different organisms, as was done in the studies of biological clocks, are common events in many new discoveries. Another common denominator is the availability of stable, long-term support to allow the resolution of difficult research problems. Finally, these research advances all emerged from peer-reviewed, investigator-initiated, individual research grants.

Recent discussions with advisory groups have also identified a number of new approaches with significant potential payoffs. Most prominently, there was widespread agreement on the need to help support significantly broader collaborative interactions than have been the norm to this time; on the need for access to a broad array of technologies; and on the need for the incorporation into basic research of quantitative disciplines such as mathematics, engineering, physics, and computer science. We have developed, together with our Advisory Council and other groups, an extensive group of initiatives reflecting these needs. Given the time available, I will only discuss two of these in detail.

Voltaire complained that doctors poured drugs of which they knew little to cure diseases of which they knew less into human beings of which they knew nothing. Since then, we have learned a great deal about drugs and diseases, but much less about the humans who are being treated. Our new pharmacogenetics initiative is designed to address this gap in understanding. Pharmacogenetics is the study of differences between individuals in the response to drugs, using the tools of genetics.

An example of what is involved is shown in the next figure [Figure 3]. This is the result of a study by an NIGMS investigator showing that the response to an anti-leukemia drug can vary significantly among the treated population. The drug is not only therapeutic, but it can be toxic if it remains in the system too long. In most people, it is rapidly degraded, and the doses are balanced to provide the maximum benefit and the minimum toxicity. However, in a small number of individuals the drug is very poorly degraded, and the results can be fatal. The study showed that the differences in response came from the variation in a gene for a specific enzyme that is involved in the degradation of the drug. Because this is now understood, a simple blood test can determine the appropriate drug levels for this treatment.

We would like to expand our ability to identify such differences between individuals and thus provide the most appropriate treatments. Consequently, we are planning to support the development of a network of multidisciplinary research groups to identify the functional variations in genes and enzymes that determine drug responses. At the same time, we will create a pharmacogenetic database in which to store, analyze, and access the information for future applications. As I noted above, access to research tools is essential for further progress, and we believe that the database I have described will be an important tool for pharmacologists and scientists generally.

The second initiative I want to describe builds on the extraordinary possibilities presented to us by the complete understanding of genomes, both the human genome and those of other organisms. Our goal at NIGMS is to arrive at a complete understanding of how cells function. Knowledge of the genes is the indispensable starting point, since they determine and regulate the production of the proteins that conduct the cell's business. The next step is to understand how these proteins function, and, as I demonstrated in the example of tubulin, this is tightly linked to an understanding of structure. As shown in the next figure [Figure 4], we propose to systematically analyze families of proteins to get a reasonably complete catalog of all the representative protein structures. We expect this to provide many benefits for investigators who are conducting research on the relationship of protein structure to function, including an understanding of the way aberrant proteins result in disease.

This initiative is the result of workshops and planning meetings over more than a year, involving several agencies (most notably the Department of Energy) and representatives of the scientific community, including scientists from both Europe and

Japan. We expect to develop this effort as a close inter-agency and international collaboration.

Last, but hardly least, the evolution of the biological sciences continues to require the incorporation of new skills in the training of investigators. We have initiated new programs to bring into biology investigators with training in quantitative disciplines; to provide support for outstanding physician-scientists to be trained in research in the areas of anesthesiology, clinical pharmacology, and trauma and burn injury; and to help postdoctoral trainees improve their teaching skills by combining a traditional research experience with mentored teaching at a minority-serving institution. We expect these and other initiatives to greatly improve and expand the capabilities of our researchers, to develop new areas of science, to broaden and enhance training opportunities, and to stimulate the entry of underrepresented minorities into basic biomedical research.

The activities of the NIGMS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this plan.

PREPARED STATEMENT OF DR. DUANE ALEXANDER

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2000 President's budget request for the National Institute of Child Health and Human Development (NICHD) of $694.1 million, an increase of $16.2 million or 2.4 percent over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, the total support proposed for NICHD is $771.7, million an increase of $18.1 million over the comparable fiscal year 1999 appropriation. Funds for NICHD efforts in AIDS research are included within the Office of AIDS Research budget request.

The activities of the NICHD are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

The National Institute of Child Health and Human Development seeks to assure that every individual is born healthy, is born wanted, and has the opportunity to fulfill his or her potential for a healthy and productive life unhampered by disease or disability. In pursuit of this mission, the NICHD conducts and supports laboratory, clinical, and epidemiological research on the reproductive, neurobiologic, developmental, and behavioral processes that determine and maintain the health of children, adults, families, and populations.

The beginning of the 21st century is an occasion to measure our accomplishments and look forward to promising opportunities. We can look back with a sense of pride on our research achievements that allow us to leave behind many disease and disability burdens that have affected the lives of children and adults throughout most of the 20th century. For example:

Infant mortality has been reduced by 70 percent since the NICHD was established 35 years ago, largely due to NICHD research that has led to new ways to treat and prevent respiratory distress syndrome, manage premature infants, and prevent Sudden Infant Death Syndrome or SIDS.

Infertility that left millions of couples unable to have children of their own during much of the last century is no longer a hopeless sentence, thanks to NICHD research that provides couples with a wide range of techniques to diagnose the causes of infertility, and numerous options to help them have their own children.

A number of causes of mental retardation including Hemophilus influenzae type b (Hib) meningitis, phenylketonuria (PKU), congenital hypothyroidism, jaundice,

measles, and rubella have become relics of the last century due to research discoveries that prevent or correct these conditions. (See attached chart.)

The social isolation and mistreatment of persons with mental retardation and physical disabilities has been greatly diminished by NICHD research. Through improved ways to teach, manage behavior, increase mobility, and remove barriers, changing attitudes have enabled people with disabilities to actively participate in our communities, including attending our schools and contributing to the workforce.

Many more children born to women infected with HIV will now enter the 21stcentury free of this virus as a result of research that has reduced the rate of virus transmission from mother to infant from 25 percent to 2 percent.

NEW RESEARCH CHALLENGES

As we leave behind some of the most feared disorders of the 20th century, many others remain unsolved, and some new conditions threaten our people.

At least 30 percent or 15 million of our nation's children fail to develop adequate reading skills for functioning in a literate society. Our poor and minority children are at the greatest risk. NICHD scientists have developed successful, research-based interventions that appear to markedly reduce the rate of reading failure. Scientists supported by the NICHD are applying and testing these methods in many locations, including nine public schools in Washington, D.C. After only one year, data indicate that reading failures have been significantly reduced at all participating schools.

While the rate of SIDS deaths has been cut nearly in half during the four years of the NICHD Back to Sleep campaign, the rate has not declined equally in all segments of society. African American and Native American babies are still more likely to die from SIDS. To address SIDS in minority and high risk communities, the NICHD has enlisted Surgeon General Dr. David Satcher and others to help reach these populations. We have also initiated a major outreach to child care centers, urging caretakers to place babies on their backs to sleep to help reduce the risk of SIDS.

Last year the NICHD, in collaboration with other NIH components, established the Women's Reproductive Health Research Career Development Centers. These 12 innovative programs will support the development of obstetrician-gynecologists to do basic, translational, and clinical research relevant to women's health, and to transfer clinical innovations to their colleagues in the profession. We will support an additional eight research centers with funds provided in fiscal year 1999.

With the increased funding in fiscal year 1999, the NICHD has also expanded its Pediatric Pharmacology Research Unit Network from 7 to 13 sites. These sites will play an increasingly important role in the health of children by quickly and safely obtaining the clinical data required for approved pediatric use of drugs. The Network also will be conducting research on genetic differences in drug metabolism in children as a way to make drugs safer for them.

RESEARCH DISCOVERIES

As we approach the 21st Century, NICHD research has sparked important discoveries that hold the promise of healthier lives for children as well as adults.

In a new study, NICHD scientists found that pregnant women infected with HIV can reduce the risk of transmitting the virus to their infants by 50 percent if they deliver by elective cesarean section before labor and rupture of their membranes. This finding contributes to the growing body of knowledge on preventing HIV transmission from mother to child.

Another important discovery may give women a new way to control their fertility without unwanted, harmful side effects. In a study using mice and rats, NICHD-supported scientists used inhibitors of enzymes in cells surrounding an egg in the ovary to prevent the egg from maturing, without disturbing other events in the female cycle. Because the eggs could not mature, they could not be fertilized. Future work will attempt to translate this advance into a product that will give women new opportunities to have children when they are wanted.

When women do give birth, new NICHD research has provided evidence that women who receive epidural anesthesia during labor and delivery do not have an increased rate of cesarean deliveries. This evidence allows women to choose epidural anesthesia for delivery without fear that it may increase their chance of cesarean section.

In the important area of medical rehabilitation research, NICHD-supported scientists have developed an improved prosthetic device that can restore hand function to both child and adult amputees. This prototype hand works by sensing the user's muscular contractions and moving the mechanical fingers in response. Early testing shows that the device is sensitive enough to permit limited piano playing.

One of the more exciting research discoveries involved new cloning techniques. In the first accomplishment of its kind, scientists have demonstrated that cloning mammals from adult cells could be accomplished repeatedly in mice. This extraordinary advance will enable researchers to answer many basic questions about how cells are programmed during normal and abnormal development. These newest cloning techniques can have a variety of applications. They can improve the breeds of livestock, eventually help derive therapeutic products, and may also help preserve rare and endangered species.

NEW INITIATIVES FOR FISCAL YEAR 2000

The beginning of a new century is also a time to look forward to new scientific frontiers. Urinary incontinence affects millions of adults and nearly twice as many women as men. Through original work under a Small Business Innovation Research (SBIR) grant, investigators have developed a new approach to correct "stress incontinence." This condition often occurs in women due to a weakening of the muscles during pregnancy or childbirth, or after a woman enters menopause. A recent discovery holds tremendous promise for restoring independence and improving the quality of life for millions of women. Using DNA technology, scientists injected special polymers around the urethra and effectively strengthened the damaged muscles found in patients with stress incontinence. Building on this advance, the NICHD, in collaboration with other Institutes, is supporting research to address a series of conditions termed pelvic floor disorders. Incontinence and pelvic organ prolapse are the most common conditions. The major factor for the development of these disorders in women is vaginal delivery. Our research will lead to a better understanding of the effects of vaginal delivery and the specific aspects of the labor and delivery process that adversely affect the pelvic floor.

Birth defects remain the leading cause of infant mortality in this country. Tremendous knowledge gaps exist in understanding birth defects and how to prevent them. To bridge these gaps, the NICHD is significantly expanding its birth defects research. We will capitalize on the revolutionary discoveries of the Human Genome Project and extraordinary advances in molecular and developmental biology. Researchers will identify target genes, environmental factors, genetic susceptibilities, and interactions between a gene and its environment. This information should provide the basis for diagnosing, treating, and preventing a wide range of birth defects.

Every year, thousands of children from homes where Spanish is the primary language spoken enter school and struggle to read in English. We do not have sound experimental evidence from the classroom indicating the most effective way to teach English reading skills to Spanish-speaking children. For instance, we do not know if these children should first be taught to read in Spanish, and then in English, nor do we know the best time to make the transition from one language to another. Building upon NICHD's successful research-based program to teach reading skills to English-speaking children, we will work with the U.S. Department of Education on a similar research program to determine the most successful ways to help Spanish-speaking children learn to read English.

Recently, the NICHD sponsored a consensus development conference on the rehabilitation of persons with traumatic brain injury (TBI). Long-term behavioral consequences remain a serious problem after TBI, and deficits in cognition, memory, and attention often result. Rehabilitation to help these individuals return to work, school, and society is costly, complicated, and often of limited success. Based on conference recommendations, a new NICHD initiative will support research applying brain imaging techniques to correlate injury with outcomes of neuropsychological testing and various rehabilitation approaches. The goal of this research will be to develop new drug or behavioral strategies to help rehabilitate persons with TBI. Plans are also under way for a TBI clinical trials network to develop and conduct multi-center studies of therapeutic techniques and procedures, as well as devices and drugs that improve the health-related function of persons with TBI.

The research supported by NICHD addresses some of the most important health and development problems facing our children and families.

PREPARED STATEMENT OF DR. CARL KUPFER

I am pleased to present the President's fiscal year 2000 budget request for the National Eye Institute (NEI) a sum of $396 million, an increase of $9.3 million (or 2.4 percent) above the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS research within the Office of AIDS Research budget request, total support proposed for the NEI is $406.5 million, an increase of $9.5 million (or 2.4 percent).

The NEI's research emphasis continues to be directed toward discovering ways to prevent, delay, and treat a wide spectrum of eye diseases and disorders. These include retinal diseases, such as age-related macular degeneration (AMD) and retinitis pigmentosa; corneal diseases; and myopia and other refractive disorders. We are working with other NIH institutes to address the serious health complications of diabetes, autoimmune diseases, and diseases of the brain. Our research initiatives have the full support of the entire eye and vision research community.

RETINAL DEGENERATIONS

The retina, the light-sensitive tissue in the back of the eye, is susceptible to a variety of diseases that can lead to visual loss or blindness. These diseases include AMD, retinitis pigmentosa, and diabetic retinopathy.

Age-related macular degeneration is the leading cause of visual loss in older adults and has an increasingly important social and economic impact in the United States. Although NEI-sponsored clinical trials have demonstrated that laser treatment reduces the extent of vision loss from the less common "wet" form of the disease, there are currently no effective treatments for the vast majority of patients with AMD who have the "dry" form of the disease. Figure 1 shows a cross-section of the eye. Figure 2 shows what an eye care professional might see when looking into the interior of a normal eye through a special instrument. Figure 3 shows changes in the eye resulting from AMD. Figure 4 depicts what a person with normal vision sees, and Figure 5 shows the visual disability of a person with AMD.

The NEI is supporting scientists across the country who are determined to find ways to prevent, delay, or perhaps cure AMD. Three major AMD clinical trials are being supported this year by the NEI. The first is the Complications of Age-Related Macular Degeneration Prevention Trial. This trial will assess the safety and effectiveness of laser treatment in preventing vision loss among patients at high-risk for AMD. The second—a set of multicenter clinical trials called the Submacular Surgery Trials—will determine whether surgical removal of abnormal blood vessels beneath the macula can stabilize or improve vision for people with AMD. The third clinical trial is being conducted as a component of the Age-Related Eye Disease Study. This research program is designed to determine whether vitamins and minerals affect the development of either AMD or cataract.

Research is also being directed toward identifying genes that contribute to the development of AMD. Techniques of molecular genetics allow scientists to examine "candidate" genes to determine whether mutations occur with a higher frequency in persons affected by AMD than in unaffected persons. Finding a genetic basis for AMD will increase our understanding of the cause of this disease and assist in developing new treatments or methods of prevention.

Retinitis pigmentosa is a group of inherited retinal degenerative diseases characterized by the progressive destruction of light sensing cells called photoreceptors. Figure 6 shows the severe visual disability of a person with retinitis pigmentosa. Researchers supported by the NEI are working to identify the genes involved in retinitis pigmentosa and related retinal degenerative diseases as well as exploring new potential therapeutic strategies, such as tissue and cell transplantation and new drugs. NEI intramural scientists have, for example, identified a specific protein that has been shown to play an important role in vitamin A metabolism in the retina. Other NEI- supported investigators have recently demonstrated that mutations in this gene are associated with Leber's congenital amaurosis, a disorder characterized by blindness at birth, and retinal degenerative changes. The development of a mouse model for this disorder bodes well for rapid progress.

DIABETES

According to "Diabetes in America," published by the National Institute of Diabetes and Digestive and Kidney Diseases, about 16 million people in the United States have diabetes, which is the leading cause of blindness in working-age adults. Blindness is the only complication of diabetes that can be prevented. A series of clinical trials supported by the NEI during the last two decades demonstrated that less than five percent of all people with diabetes need to lose their vision if the treatment recommendations from the clinical trials are followed. Despite this success, intensive research continues on finding improved methods to prevent these complications. Research opportunities are discussed in the recommendations of the Congressionally- mandated report of the Diabetes Research Working Group.

HEALTH DISPARITIES AND MINORITIES

Eye care problems in our country's minority populations need to be better understood. The NEI is supporting several studies designed specifically to address eye dis-

ease in underserved populations. For example, Hispanics are the fastest growing minority population in the US. According to "Diabetes in America," a high percentage about 9.6 percent of the Mexican-American population have diabetes. Yet, the absence of data on visual impairment for Hispanics in the United States hampers the development of appropriate eye health services. Because of this, the NEI is supporting research to determine the prevalence and cause of blindness and visual impairment in 4,500 Mexican Hispanics over age 40 residing in Arizona and in 6,000 Mexican Hispanics residing in an urban Los Angeles neighborhood. This information will provide evidence of the burden of visual impairment and blindness in the Mexican Hispanic community and serve to direct resources appropriately toward the major eye health needs in this population.

Glaucoma is three to four times as common in Blacks as in Whites, and blindness from glaucoma is six times as common in Blacks than in Whites. Last year, an NEI-supported investigation found that Blacks and Whites with advanced glaucoma respond somewhat differently to two surgical treatments for the disease. Scientists found evidence to suggest that Blacks with advanced glaucoma may benefit more from a regimen that begins with laser surgery, while Whites may benefit more from one that begins with an operation called a trabeculectomy.

CORNEAL DISEASE

The cornea is the transparent tissue at the front of the eye that helps direct incoming light onto the retina. Good vision depends on a clear and transparent cornea. Recent NEI-funded research has led to great progress in understanding and treating corneal disorders. For example, researchers have established an effective treatment for a particularly painful corneal disease—herpes of the eye. This virus can produce a painful sore on the surface of the eye and cause inflammation of the cornea. Scientists found that long-term treatment with the anti-viral drug acyclovir, given by mouth, reduced by 41 percent the probability that any form of herpes of the eye would recur in patients who had the infection in the previous year. This is a major step forward for people with the nearly 50,000 new and recurring cases of herpes of the eye diagnosed each year in the United States, according to an article in "Archives of Ophthalmology."

MYOPIA

About 60 percent of the American population have refractive errors—that is, they need eyeglasses or other corrective measures to see better. Myopia, or nearsightedness, is a common condition in which images of distant objects appear blurry. Concerted efforts in a number of laboratories over the past two decades have led to the realization that myopia begins in early life and raises the possibility that it can be prevented or reversed with early detection and intervention. Recent observations have identified specific visual performance problems that put a child at high risk for the development of myopia. New methods for the clinical treatment of myopia and other refractive disorders in humans are now being tested in several clinical trials.

One of these trials that the NEI is conducting is evaluating whether the use of special spectacle lenses can slow the progression of myopia in young children. Studies such as these suggest the real possibility of effective approaches to prevent or slow down the progression of myopia.

Future vision research with emerging technology holds great promise for understanding the development and normal function of the visual and neural systems. Progress in the diagnosis and treatment of clinical disorders that impair vision, such as amblyopia, nystagmus, and strabismus, depends on this research.

AUTOIMMUNE DISEASES

Little is known about the factors that determine susceptibility of the visual system to autoimmune diseases. The NEI's research program is actively investigating the cause of a number of autoimmune diseases. These include uveitis, a potentially blinding eye condition, and dry eye, which is a symptom of Sjogren's syndrome. Dry eye is more common in women, especially after menopause.

NEI investigators are pioneers in a new approach called oral tolerance therapy for treating patients with presumed autoimmune disorders. Researchers at the NEI discovered a protein from the eye that, when administered orally, allows people with uveitis to stop taking, or reduce dependence on, toxic drug therapy. Additional studies are using oral tolerance therapy to treat other inflammatory eye diseases. The NEI is also an active participant in several trans-NIH initiatives on autoimmunity.

LOW VISION

It is important to emphasize that as the size of the older adult population increases, the number of people with visual impairment from AMD and other aging-related diseases will increase. About one in eight Americans is now 65 or older, according to the US Census Bureau. When you add declining mortality rates and population demographics, such as the "baby boomers," the number of older people with low vision will grow dramatically in the years ahead. Visual problems can have a devastating impact on quality of life. Low vision interferes with an individual's ability to perform daily routine activities, such as reading the newspaper, preparing meals, or recognizing faces of friends.

To help address this concern, the NEI, through its National Eye Health Education Program, is developing a program to educate the public about low vision and the benefits of vision rehabilitation. This program also will provide information on services and devices available to help people cope with vision loss. The program will consist of a broad-based consumer media campaign; resources for health care professionals and social service organizations; and a community outreach program for both the general public and health care and social service professionals.

The activities of the NEI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. KENNETH OLDEN

Mr. Chairman and Members of the Committee: I am appearing before the Committee to present the President's budget request for the National Institute of Environmental Health Sciences (NIEHS) for fiscal year 2000, a sum of $390.7 million, an increase of $9.1 million (2.4 percent) over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support proposed for NIEHS is $397.9 million, an increase of $9.3 million over the fiscal year 1999 appropriation. Funds for NIEHS efforts in AIDS research are included within the Office of AIDS Research budget request.

Over the past 35–40 years, the United States has made remarkable progress in promoting economic growth while improving the environment and reducing adverse health threats to humans and the ecosystem. We can celebrate the fact that we have greatly enhanced the quality of our lives through the development and use of agricultural products and industrial technologies, the refinement and use of fossil fuels and other natural resources, the development of safer food and water processing and storage capabilities, and the development of efficient transportation systems.

However, some of these technological innovations and processes have produced unintended by-products that pollute the environment and pose threats to human health and the ecosystem. Because of the introduction of new technologies and the expansion of the global economy, the opportunities and challenges in environmental health research have changed over the years. Managing today's risks requires consideration of susceptibility and low-dose exposures, use of high-throughput screening and environmental genomics, and establishment of interagency partnerships to ensure that all stakeholders are involved.

We have not yet achieved this optimal state and the consequence is that, all too often, important public health decisions are made in the face of significant uncertainties. Current risk assessment approaches frequently use default assumptions which reflect an inadequate scientific foundation for assessing risk. The NIEHS is improving this situation through programs in mechanism-based toxicology that draw on the tools of molecular biology to provide approaches for the development of more accurate and inexpensive methods to perform not only identification of environmental hazards, the first step in risk assessment, but also contribute to determining quantitative dose-response relationships and establishing biomarkers for estimating human exposure and toxicity.

EIGHT CRITICAL RESEARCH AREAS

In previous appearances before this Committee, I have consistently emphasized the need to invest in eight critical areas of research. As shown in Exhibits #1A and #1B, these areas are: testing for carcinogenicity and toxicity, differences in susceptibility, children's health, health disparities, gender differences, exposure assessment, complexmixtures, and mechanisms of toxicity/carcinogenicity. I indicated that these models hold considerable promise for being less costly, less time consuming, and use fewer animals. Last year, I presented a progress report on our efforts to develop genetically-engineered, or transgenic, mice to assess chemicals for their carcinogenic potential. For many years the major impediment in environmental health research has been the lack of appropriate animal models to investigate the molecular interactions between genes and environmental agents.

Today, I want to discuss three of the areas of research shown in Exhibit #1. First, I want to bring to your attention the urgent need for the development and validation of methodologies for use in assessing the toxicity of novel protein/glycoprotein products generated by the burgeoning biotechnology industry. Then, I would like to describe some of our research in the area of children's environmental health and in understanding gender differences in response to environmental agents.

SAFETY ASSESSMENT OF THERAPEUTICS

In previous testimony, I emphasized the need for high-throughput assessment of toxicity as a priority for the Nation. The focus of my concern was on synthetic and natural chemicals used in various commercial products. I indicated that it was unrealistic to expect that we could ever evaluate the thousands of potentially useful chemicals synthesized each year using current methodology. To meet the new demands, we must develop new methodologies for toxicity testing that are less time consuming and less costly. In other words, the Nation's capacity to synthesize new chemical products far exceeds our ability to evaluate them for possible adverse health effects.

However, the problem of having inadequate models for assessment of toxicity is not limited to the synthetic and natural chemicals typically evaluated in the National Toxicology Program (NTP). In recent years, fundamental advances in the therapeutic discovery process have opened the door to the development of a vast array of potential agents for the prevention and treatment of disease. New discovery techniques such as combinatorial chemistry, high-throughput screening, and mass spectrometry have provided drug discovery engineers with the ability to generate thousands of strategically-designed compounds. Coupled with the anticipated explosion of therapeutics targeted at the genetic mechanisms of disease, this has the potential to create a similar "bottleneck" in the drug development processes. The use of conventional toxicity-assessment methods will not allow the testing of all the promising compounds that are being developed because of the time required and the amount of research resources required. Therefore, new approaches are needed for determining the safety of new therapeutic agents early in the drug discovery process.

The current efforts of the NIEHS to develop surrogate and alternative methods of toxicological assessment of environmental agents will provide an opportunity to lead this research endeavor. We believe that many of the safety assessment methods that are currently being developed and evaluated will prove to be effective in determining the safety of new pharmaceutical compounds early in the discovery process. As a result of the efforts of the NIEHS to evaluate short-term alternatives to the conventional two-year rodent bioassay for carcinogenic potential, the Institute has become a partner in a world-wide effort being conducted within the pharmaceutical industry under the aegis of the International Life Sciences Institute (ILSI) in Washington. The pharmaceutical industry, in partnership with the NIEHS, has developed a coordinated project in which promising new transgenic models are being evaluated for their utility in drug safety assessment.

Early in 1997, international pharmaceutical and regulatory communities recognized the limited utility of conventional rodent toxicity and carcinogenicity studies and proposed a new scheme for carcinogenicity testing of pharmaceuticals. The Alternatives to Carcinogenicity Testing Committee was formed under the Health and Environmental Sciences Institute of ILSI. NIEHS scientists serve on the steering committee and as scientific advisors, and the NTP is a participant in the project. This government/industry partnership is a prototype effort which has laid the foundation for the rapid development and evaluation of surrogate methodologies. The project has provided NIEHS with the experience and leadership to promote the development of innovative and rapid new methodologies. Toward this end, we have begun the development of a "tox chip" that will utilize DNA microarray technology

to search for surrogate biomarkers of organ-specific toxicity and carcinogenic potential of chemicals. The NIEHS thus can serve as the focal point in what some believe to be the most exciting innovation in toxicologic assessment and toxicological research in the past decade.

CHILDREN'S HEALTH

Last year I related to you our plans to improve children's environmental health through new research centers we were arranging to co-fund with the Environmental Protection Agency (EPA). I am pleased to report that eight centers have been established, focusing on the areas of environmental influences on asthma and development. The need for this research is revealed in Exhibit No. 2, which shows the rapid development of an organ system in a child. Here you see how the complexity of a child's brain increases during the first two years of life. The branching indicates the formation of nerve connections, a critical part of the brain's machinery. It is during this period of development when the elaborate network of the brain is being constructed that it is exquisitely susceptible to neurotoxic environmental agents such as lead, mercury, and polychlorinated biphenols. Just as the brain is rapidly developing at this stage of life, so too, are other organ systems.

As you know, there is great concern that exposure standards that are set to protect adults do not adequately protect children. The various research activities that the NIEHS supports to address those concerns are shown in Exhibits No. 3A and No. 3B.

The NIEHS is supporting research on many important aspects of children's health. We are examining the effects of early pesticide exposure on the brain, immune system, and reproductive system. We continue to sponsor an intervention trial on the ability of the chelating agent, Succimer, to reduce blood lead levels and to reverse neurological deficits associated with early, low-level lead exposures. We have initiated a study of Attention Deficit/Hyperactivity Disorder to identify environmental components of this disorder. We are interested in expanding the Agricultural Health Study, done in concert with the National Cancer Institute, to determine if nitrate exposures trigger juvenile diabetes. The Institute has a large, ongoing study of cleft palate birth defects to determine the environmental and genetic components of this all-too-common birth defect. The Institute is also continuing its asthma prevention and intervention studies, done in collaboration with the National Institute of Allergy and Infectious Diseases that examine the effect of reducing allergen exposure on incidence and risk of asthma.

GENDER DIFFERENCES

Men and women can have very different disease risks, can react differently to the same medication, and can even have different outcomes from such surgical procedures as cardiac bypass surgery. In the context of environmental health, men and women can also have different responses to environmental agents. The NIEHS has a long history of exploring how gender affects susceptibility to environmental compounds. For example, research effort is being done to understand the consequence of exposure to endocrine disrupting compounds. These compounds have been suggested as causing a decrease in sperm count in men, an increase in breast cancer risk in women, and increased risks of testicular and prostate cancer in men.

The NIEHS is also pursuing the development of environmental cohorts to help understand disease risks as a function of environmental exposures and gender. The first of these, the Sisterhood Study, would focus on breast cancer. Women who have a sister diagnosed with breast cancer would be recruited. Their environmental exposure history would be recorded, serum samples would be taken, and their health would be monitored for a long period of time. As these women developed breast cancer, their environmental exposures could be correlated with their disease risk. This type of prospective study has great potential for defining the environmental components of breast cancer and other diseases. For example, using a prospective study design, an NIEHS grantee showed that the pesticide dieldrin doubled the risk of a woman developing breast cancer.

Another important area in which there are gender differences is that of autoimmune diseases such as multiple sclerosis, diabetes mellitus, and rheumatoid arthritis. Almost all autoimmune diseases occur more often in women than in men; in some of these diseases, more than 90 percent of patients are female. The NIEHS, in collaboration with other components of the NIH, as well as the EPA and private foundations, hosted a workshop on "Linking Environmental Agents and Autoimmune Diseases." In order to stimulate research on the role of environmental agents in autoimmune diseases, recommendations from this workshop will be formu-

lated into a Request for Applications (RFA) to be jointly sponsored by the NIEHS and other NIH components.

The activities of the NIEHS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

These are only a few of the many exciting initiatives the NIEHS will be pursuing in the year to come. I believe that the ultimate outcome from these efforts will be a more informed public policy and better prevention strategies to protect public health.

PREPARED STATEMENT OF DR. RICHARD J. HODES

Mr. Chairman and Members of the Committee: The President in his fiscal year 2000 budget has proposed that the National Institute on Aging (NIA) receive $612.6 million, an increase of $14.3 million (2.4 percent) over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support proposed for the NIA is $614.7 million, an increase of $14.4 million over the fiscal year 1999 appropriation. Funds for NIA efforts in AIDS research are included within the Office of AIDS Research budget request.

The activities of the NIA are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for the NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. The NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. The NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

I am pleased to report the NIA's recent progress, through research, toward extending the healthy, active years of life. Aging well is critical as the population of older Americans begins a rapid expansion. Fortunately, studies are showing that America's older population is becoming healthier and more fit. Previously reported findings of substantial declines in the rates of disability among older persons have recently been confirmed by an independent team of investigators using different sources of data. Notably, improvements in functioning were found to be greatest among those 80 and older, and the improvements in disability rates have accelerated from 1982 to the present. In further analyses, these decreases in disability have been documented in men and women, as well as among minorities. The NIA continues to promote research on the causes and economic consequences of the decline in disability rates with the goal of further accelerating these improvements.

ALZHEIMER'S DISEASE AND BRAIN BIOLOGY RESEARCH

Alzheimer's disease (AD), the most common form of dementia, affecting as many as four million older persons, results from abnormal changes in the brain that begin long before memory loss and other clinical symptoms become apparent. AD eventually leaves patients oblivious to the outside world and unable to perform even the most basic tasks, with devastating consequences to individuals, families, and society. During the last 20 years, scientists have produced an extraordinary body of research findings relevant to AD. Based upon these advances, the NIH is launching an AD Prevention Initiative to expedite the search for underlying causes and to make a concerted assault on disease development and progression, in collaboration with other Federal agencies and the private sector. The Prevention Initiative will invigorate efforts to discover new treatments, risk factors, methods of early detection and diagnosis, and strategies for improving patient care and alleviating caregiver burdens. The initiative will also expedite movement of promising new treatments and prevention strategies into clinical trials. For the first time, drugs will be tested in clinical trials for their ability to delay or prevent the onset of AD. The success of this initiative would thwart the impossible demands that unchecked growth of the population afflicted with AD would place on individuals, families, and society.

The AD Prevention Initiative will benefit from an explosion of findings on the underlying causes and pathology of AD. The two pathologic hallmarks that scar the brains of people with AD are senile plaques and neurofibrillary tangles. Tangles are the wreckage of microtubules that comprise the brain cells' internal transportation system. A protein known as tau normally acts to maintain the integrity of this system, and in the past year researchers provided evidence indicating that abnormalities in tau may be responsible for the formation of neurofibrillary tangles and death of brain cells. Scientists identified several mutations in the tau gene on chromosome 17 that are associated with and appear to cause one form of familial dementia, providing the first direct evidence that mutations in tau can lead to disease. Further research will target tau's role in AD and related neurodegenerative diseases, including Parkinson's disease. The NIA is collaborating closely with the National Institute of Neurological Disorders and Stroke, National Institute of Mental Health, National Institute of Nursing Research, and other NIH institutes to stimulate rapid progress on AD, Parkinson's disease, and other neurodegenerative diseases.

Another exciting advance with great promise has overturned long-held beliefs that cells of the adult brain cannot reproduce. Investigators have shown that rodents, non-human primates, and humans make new, mature brain cells, even in older adults, in the part of the brain used in forming long-term memory. In one experiment, thousands of these cells were found to be produced each day. Intriguingly, the studies also showed that more new brain cells survived in mice exposed to stimulus-enriched environments, and that stress can substantially reduce the production of new brain cells. This finding is a major step forward, opening the way to enhancing nerve cell development and to the possibility of replacing nerve cells lost through age, trauma, or disease.

BIOLOGY OF AGING

Research on the biology of aging has led to a revolution in aging research. New findings about what causes cells to mature, to lose the capacity to reproduce, and eventually to die promise to provide valuable insights about the genesis of disease. In early 1998, major advances were made in understanding the role of telomeres, DNA segments on the ends of chromosomes that shorten with each cell division until, at a critical length, cell division ceases. Telomeres have been regarded as the cell's "molecular clock." The enzyme telomerase adds DNA segments to the ends of chromosomes, compensating for telomere loss. Researchers demonstrated that, by inserting the gene for telomerase into normal, telomerase-negative cells, shortened telomeres grow longer, and the cells replicate far beyond the limits observed for normal cells while retaining the function of young, normal cells. This finding may provide a key to unlocking a part of the biology of aging and also has important implications for cancer research.

An additional advance on aging mechanisms was recently reported for yeast. During the normal aging process, yeast cells begin to accumulate so-called DNA circles that are distinct from the DNA on chromosomes. Recently, researchers found that some yeast, with a specific gene alteration, have shorter life spans and show premature signs of aging. They discovered that this accelerated aging is associated with a more rapid accumulation of DNA circles. Scientists now think the buildup of DNA circles may be under genetic control and may function as an "aging clock" in yeast. Researchers have also discovered that the abnormal yeast gene associated with accelerated yeast aging and accumulation of DNA circles is similar to a human gene associated with Werner's syndrome, a deadly disease characterized by decreased life span and symptoms of premature aging. Lessons learned from aging yeast are thus guiding researchers' efforts to discover therapies for diseases associated with aging.

Other experimental organisms, including the worm C. elegans and the fruit fly D. melanogaster, have helped in the search for gene mutations that affect an organism's life span. This year, researchers studying fruit flies showed that the mutant methuselah gene, named for the long-lived Biblical patriarch, increases the flies' life span by an average of 35 percent over flies that lack this mutation. The mutant flies also were significantly more able to tolerate stress and heat and were more resistant to a herbicide that can damage cells. Ongoing research will attempt to identify how the methuselah gene mutation confers these characteristics more favorable for survival. This signal advance confirms the existence of genes that directly regulate aging and should lead to better understanding of mechanisms relevant to health in humans.

The technology of molecular genetics can be valuable in other aspects of aging research. For example, humans lose up to a third of skeletal muscle mass and strength as they age. In 1998, investigators successfully used a gene therapy approach in mice to show that it may be possible to prevent age-related muscle atro-

phy and preserve muscle size and strength in old age. The new treatment increased muscle strength by 15 percent in young adult mice and, even more strikingly, by 27 percent in older mice. For older mice, muscle strength was restored to levels equivalent to those normally observed in young adulthood. To produce these results, the researchers engineered a virus to deliver into mouse muscle a normally-occurring gene called insulin-like growth factor I (IGF-I), which plays a critical role in muscle repair and is believed to become less effective with age. While technical and ethical issues must be overcome if the procedure is to be tested in humans, this therapeutic approach has promise for reducing age-related muscle loss, for other applications involving muscle strengthening, and for treating diseases of muscle.

REDUCING DISEASE AND DISABILITY

NIA research explores strategies that can significantly improve the quality of life of people of all ages. Exercise is a prime example of a behavior that has been proven to improve function and quality of life as we grow older. Even in the very old, simple exercises can maintain and even restore strength and stamina, flexibility, and balance. To encourage people to start an exercise habit and stick with it, the NIA, with Senator John Glenn, the National Aeronautics and Space Administration, and other Federal agency partners, launched a national education campaign on exercise for keeping fit after 50. The campaign is linked to an easy-to-follow, home-based guide to exercising that is available free of charge. The Internet version of the guide, which can be found at http://www.nih.gov/nia/health/general/general.htm, also provides animated versions of some of the exercises.

Lifestyle changes can also be effective in reducing the risk of major disease. While blood pressure medications can substantially reduce the risk of cardiovascular disease, the leading cause of death and major cause of disability in the elderly, they can also cause adverse drug interactions and other side effects. Medications can also be very costly. The NIA and the National Heart, Lung, and Blood Institute co-funded the Trial of Nonpharmacologic Interventions in the Elderly (TONE) to test whether modest weight loss, reduction in sodium intake, or both can reduce or eliminate the need for medication in men and women ages 60 to 80 with mild high blood pressure. People who participated in the trial had previously been successful in controlling their blood pressure with a single antihypertensive medication. During the study, medication use was gradually withdrawn under medical supervision as the lifestyle changes were implemented. At the end of the trial, about one-third of the participants on either salt reduction or weight loss programs were able to maintain normal blood pressure without medication. Overweight participants who both lost weight and reduced sodium intake realized the greatest benefits; 44 percent of this group were able to control blood pressure without medication, compared with 16 percent of those receiving usual care. The TONE thus concluded that modest reduction in sodium intake and weight loss could provide a feasible, effective, and safe nonpharmacologic therapy for hypertension in a significant number of older persons who otherwise would be prescribed medications. TONE has important implications for physicians and public health professionals because it shows that older people with high blood pressure are able to make and sustain lifestyle changes. These changes are possible even after decades of relative physical inactivity and sub-optimal eating habits.

Loss of bone mass due to osteoporosis results in millions of fractures each year in the U.S., causing substantial pain, dysfunction, and death in later life. The NIA and the National Institute of Arthritis and Musculoskeletal and Skin Diseases collaborate on research to prevent osteoporosis, including studies of hormone replacement toward this end. One of these studies measured the naturally occurring internal levels of estrogen in nearly 900 women over age 65 and found that women who had measurable blood levels of estrogen—much lower than the levels currently achieved by taking hormone supplements—had less than half the risk of experiencing a subsequent hip or vertebral fracture than women with undetectable levels of estrogen in the blood. These studies suggest that even very low-dose estrogen supplements may lower the risk of postmenopausal fractures in men and women without causing adverse effects sometimes associated with estrogen therapies. NIA investigators at a Claude D. Pepper Older Americans Independence Center are conducting preliminary clinical research to investigate the impact of low-dose estrogen supplementation on markers of bone strength and turnover.

Researchers have been trying to identify factors that place certain drivers at increased risk for vehicular crashes as an alternative to imposing unfair, arbitrary age limits on driving. Recently, investigators reported on a study that tested 294 older drivers on a novel measurement of visual processing skills and then followed their driving experience for three years. The skills tested included visual processing speed

and the ability to divide attention while driving. Drivers with a 40 percent or greater impairment in these skills at the beginning of the study were more than twice as likely to incur a crash during the followup period than those with lesser impairment. Valid tests to assess driving ability may enable people of all ages to drive as long as they can safely do so and can help drivers and their families to decide when the risks are too great to continue.

Over the past year, aging research has maintained a rapid pace of discovery in basic science and has fueled the emergence of important opportunities for interventions to delay or to prevent diseases and disabling conditions that were once thought to be a normal part of aging. These advances hold the promise of adding life to years as our nation ages.

PREPARED STATEMENT OF DR. STEPHEN I. KATZ

Mr. Chairman and Members of the Subcommittee: I am pleased to present the President's budget request for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for fiscal year 2000, a sum of $310 million. Including the estimated allocation for AIDS research, total support proposed for the NIAMS is $314.75 million, an increase of $7.368 million or 2.4 percent over the comparable fiscal year 1999 appropriation. Funds for NIAMS efforts in AIDS research are included within the Office of AIDS Research budget request.

I am honored to appear before this Subcommittee, to express my appreciation for the fiscal year 1999 appropriation, to share with you how we have invested these funds, and to talk about some of the scientific opportunities that we plan to pursue in fiscal year 2000. The fiscal year 1999 budget increase provided an opportunity for us to invest in key areas of public health needs, with a particular emphasis on clinical studies. Specifically we are launching a new clinical study of low back pain, expanding our clinical and basic studies of the many autoimmune diseases that we are concerned with, and investing in the next generation of clinical researchers. Let me tell you briefly about each of these.

First, I want to expand on low back pain—a major problem for our society that affects people at home, at work, and in their recreational activities. We have initiated a multicenter clinical trial on low back pain that will assess the effectiveness of back surgery versus non- surgical treatment for the three most common diagnoses for which surgery is performed. The study has the potential to have a major impact on clinical practice and on costs of medical services. Second, with regard to autoimmune diseases, we are encouraging additional research on the molecular pathways and the genetic basis of the target organ that is involved in autoimmune diseases—what is it about the kidney, the brain, or the heart that makes them the target in lupus in some people and not in others, and what is it about the hair that makes it the target in alopecia areata, for example. Third, we are encouraging pilot clinical trials in rheumatic and skin diseases as well as clinical trials in osteoporosis. Fourth, we are responding to concern about building the pipeline of researchers who can conduct clinical studies by making a commitment to increase our support of training and sustaining clinical investigators who can work with basic scientists and use their knowledge to improve public health. These exciting new studies and support mechanisms are important additions to our research portfolio of fundamental and clinical studies of bone, muscles, skin, and joints. Now I want to share with you some highlights of progress and other opportunities in the NIAMS.

AUTOIMMUNITY

While our understanding of autoimmune diseases has improved significantly, researchers do not yet fully understand why some patients are affected with diseases in which their bodies' immune cells attack various vital organs. Diseases in this category include rheumatoid arthritis, systemic lupus erythematosus, Sjogren's syndrome, scleroderma, alopecia areata, and many blistering skin diseases—all potentially devastating chronic diseases which exact a huge toll in human suffering and economic costs. This year, we have witnessed significant, exciting research advances in several of these diseases.

Rheumatoid arthritis is a chronic autoimmune disease that causes progressive destruction of the joints in affected people causing pain, suffering, and decreased mobility, and it has compromised quality of life and productivity for many Americans. There are now new medications that have been developed for patients with rheumatoid arthritis. This development is an excellent example of how fundamental knowledge can have an impact on health. Basic studies in recent years identified a particular molecule (called tumor necrosis factor alpha) that is important in caus-

ing the joints to become inflamed, and pharmaceutical companies were then able to target this molecule and try to eliminate it before it destroys the joint. The new treatments are either artificial decoys that bind the culprit molecule or are antibodies to the culprit molecule. Other new drugs for rheumatoid arthritis block enzymes that enhance joint inflammation. These drugs, known as COX–2 inhibitors, are thought to target joint inflammation more specifically than do the currently available nonsteroidal anti-inflammatory drugs. There is also a newly available immunosuppressive drug that targets fast-growing blood cells that are involved in joint inflammation in patients with rheumatoid arthritis and other forms of inflammatory arthritis. As more disease-causing or amplifying molecules or cells are identified, they will be targeted for elimination in a similar manner.

On a more fundamental level, NIAMS intramural scientists continue their forefront research on the genetics of rheumatoid arthritis and have provided critical information on the role of genes in influencing disease susceptibility in animal models of rheumatoid arthritis and other autoimmune disease. During the next few years, we are going to invest in developing these animal models further because of their relevance to our ongoing genetic studies of families affected with rheumatoid arthritis.

Scleroderma is an autoimmune disease that occurs much more frequently in women than in men, and it is characterized by widespread hardening of the skin and other tissues. NIAMS- supported researchers have made progress in three areas of research related to scleroderma: (1) a new study in Oklahoma Choctaw Native Americans suggests that the gene for the protein fibrillin–1 is a possible susceptibility gene for scleroderma; this finding is particularly significant because we know that this gene plays an important role in an animal model of scleroderma; (2) an intriguing discovery that has identified the persistence of fetal cells in the skin and blood of women with scleroderma suggests that these persisting immune cells may start attacking the patients' own vital organs; and (3) a potentially very important study that has improved our understanding of the molecular pathways of fibrosis—the determination that cells from scleroderma patients have twice as many receptors for a particular molecule, transforming growth factor (TGF), as cells from persons without scleroderma. We know that the binding of TGF to its receptors sends a signal to the cell to produce more collagen. This cycle then results in increased collagen formation and hardening of tissues. These three advances provide exciting research avenues to be pursued to improve our understanding of scleroderma.

Alopecia areata is another example of an autoimmune disease and it is the most common form of acquired hair disease (excluding male pattern baldness). There has been a real expansion in our understanding of normal hair growth, and much of this enhanced knowledge comes from critical animal models that have been developed for studying this disease. In November 1998, the NIAMS joined the National Alopecia Areata Foundation in cosponsoring the Third International Research Workshop on Alopecia Areata at which research advances and many promising opportunities in understanding hair development, in developing better approaches to animal models, in searching for the antigenic targets in hair, and in attempting to define a better classification of disease were identified. We plan to develop a program announcement in this area in fiscal year 2000.

OSTEOPOROSIS

Studies of basic bone biology have given us important insights into how bone is built up and broken down normally in the body, and how this balanced process can go awry in conditions like osteoporosis, where the bone thins and fracture susceptibility increases. Research has increased our understanding of why estrogens are beneficial for people with osteoporosis, and why steroid drugs called glucocorticoids are deleterious and cause thinning of bones. Glucocorticoids are important in the prevention of rejection of transplanted organs and in the treatment of many common inflammatory diseases like rheumatoid arthritis and asthma, but their use can cause bone loss that leads to fractures and disability. New observations suggest that the bone loss may be explained in part by a reduction in the rate at which bone-building cells form, along with higher rates of cell death in bone. Investigators are currently attempting to identify the pathways by which these changes occur.

The NIAMS is also expanding its studies on osteoporosis from those primarily focused on women to those seeking to understand the causes and improve the treatments for men with osteoporosis. Osteoporosis is a significant public health issue that affects many Americans and threatens to affect many more as our population ages. The good news is that we have substantial research progress in this area. We have improved diagnostic approaches to osteoporosis, we have effective treatments available that were not on the market a decade ago, and we know much more about

lifestyle practices that enhance bone health. Another initiative that the NIAMS is undertaking is the study of combinations of drugs for osteoporosis. This is an area in which the federal government can provide real leadership, because companies generally do not support studies that combine their drug with a drug from another company. The use of various drugs in combination has the potential to make an important contribution to the treatment of osteoporosis and thus to improve public health. Finally, information dissemination about osteoporosis, and indeed every other disease under the purview of the NIAMS, to all segments of the population remains a key priority of the Institute. The NIAMS joined with six other components of the Department of Health and Human Services in awarding a cooperative agreement for the NIH Osteoporosis and Related Bone Diseases—National Resource Center. Also, in fiscal year 2000 the NIAMS and other NIH institutes and other federal agencies will sponsor a Consensus Development Conference on Osteoporosis that will serve to educate physicians as well as other health care providers and the public with vital substantiated information about the diagnosis, treatment, and prevention of osteoporosis.

HEALTH DISPARITIES

The NIAMS is concerned that there are disparities in the health status of Americans. One example is the finding from studies in osteoarthritis that African American people have much lower rates of total knee replacements than whites, even when adjusted for age, sex, and insurance coverage. Understanding the reasons for this disparity will help us to target particular populations to develop prevention strategies. In addition, studies in behavioral research have demonstrated that Hispanic and African-American lupus patients have more severe disease at the time of presentation than Caucasian patients. Genetic and ethnic factors appear to be more important than socioeconomic factors in influencing disease activity at the time of disease onset. Furthermore, differences in the disease course and outcome in lupus patients also appear to be caused by many factors—including the ways in which patients themselves respond to their illness. We already know a lot about the importance of "self-efficacy" and how patients manage their disease. Many chronic diseases like osteoarthritis and lupus affect women and minorities disproportionately, and we are actively seeking to understand the causes of these gender and ethnic differences.

EXERCISE PHYSIOLOGY AND SPORTS INJURIES

Every day more and more Americans are undertaking some sort of fitness program or exercise activity. While this is good news—as we are all encouraged to be more active—it is also accompanied by a significant increase in sports injuries, particularly in women. We are not yet sure why, but women are particularly vulnerable to some types of injuries when they participate in sports, especially injuries of their knee joints. We are joining with the American Academy of Orthopaedic Surgeons to sponsor a meeting on women and sports injuries this June, just prior to the 1999 Women's World Cup Soccer Tournament in Washington, DC. We intend to use this opportunity to put a spotlight on women in sports, and to try to understand the particular injuries that women suffer. We are working to identify the causes of sports and exercise injuries, and to develop effective strategies to avoid and treat them.

MEDICAL RESEARCH MAKES A DIFFERENCE IN PEOPLE'S LIVES

As the illustrations just cited reveal, considerable progress has been made in identifying and alleviating many of the physical and social consequences of chronic diseases, and the investigations underway and planned promise to continue to improve life. We are proud of the achievements of the scientific programs we have supported, of the individual scientists who devote their lives to research, and of the value of research to every day life. We remain very clear in our goal: to support high quality science that will continue to improve the health of the American people.

The activities of the National Institute of Arthritis and Musculoskeletal and Skin Diseases are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. JAMES F. BATTEY, JR.

Mr. Chairman and Members of the Committee, the President in his 2000 budget has proposed that the National Institute on Deafness and Other Communication Disorders receive $235.3 million, an increase of $5.6 million over the non-AIDS portion of the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIDCD is $237.2 million, an increase of $5.6 million over the fiscal year 1999 appropriation. Funds for NIDCD efforts in AIDS research are included within the Office of AIDS Research budget request. I am honored to appear before you as the Director of the National Institute on Deafness and Other Communication Disorders (NIDCD).

NIDCD conducts and supports research and research training on normal processes and disorders of hearing, balance, smell, taste, voice, speech, and language. These processes are fundamental both to the way people perceive the surrounding world and to their ability to communicate effectively with other individuals. As we approach the end of the century, effective human communication is an increasingly important requirement for a wide range of employment opportunities. Within the last year, we have witnessed outstanding research progress by NIDCD-supported scientists and clinicians, progress further accelerated by the efforts of other institutes at the NIH. This progress is lighting the path for ongoing and future research studies to achieve a pressing goal: to help individuals with communication and sensory systems disorders.

EARLY IDENTIFICATION OF HEARING IMPAIRMENT: EARLY INTERVENTION RESULTS IN BETTER LANGUAGE SKILLS

Since about 33 children are born each day in the United States with a significant hearing impairment, early identification of these affected children has become an important public health objective. Recent results from NIDCD-supported research show that children whose hearing impairments are identified by six months of age, and who consequently receive appropriate intervention, demonstrate significantly better language scores than children whose impairment was initially identified after six months of age. For children with normal cognitive abilities, this language advantage was found across all tested ages, communication modes, degrees of hearing loss, and socioeconomic strata.

In 1993, an NIH Consensus Development Conference on the Early Identification of Hearing Impairment in Infants and Young Children recommended universal screening of all infants for hearing impairment. In the near future approximately 19 states will implement programs to screen all neonates for hearing impairment before discharge from the hospital. [Exhibit 1] This number is expected to increase rapidly in the next decade. Implementation of intervention strategies that optimize language skills is a necessary sequel to early identification.

The need to define and validate optimal intervention strategies for infants with all degrees of hearing impairment is clear. In March 1998, the NIDCD convened a Working Group on the Early Identification of Hearing Impairment to provide advice on the most pressing research questions regarding diagnostic and intervention strategies that follow neonatal hearing screening. The workshop focused on strategies that are appropriate immediately after an infant is referred from the screening program, depending on the degree of hearing impairment identified. Current studies indicate that approximately 10 to 20 percent of the infants identified through neonatal hearing screening have profound hearing impairment. The other eighty to ninety percent have lesser, but varied, degrees of hearing impairment, defining additional populations of infants for whom optimal intervention strategies remain to be developed and validated through research. In October 1998, NIDCD solicited grant applications to develop and validate these needed intervention strategies. We anticipate the results of a recently concluded, multi-center collaborative project which will provide critical information regarding efficacy and cost of different screening protocols.

DISCOVERING THE GENES UNDERLYING HEREDITARY HEARING IMPAIRMENT

Roughly one child in two thousand born in the United States has hereditary hearing impairment of sufficient severity to compromise the development of normal language skills. Some of these children have hearing impairment together with other problems, a condition known as syndromic hearing impairment. Many of the genes where mutations cause syndromic hearing impairment have been identified. [Exhibit 2] However, about seventy percent of children with hereditary hearing impairment have no obvious associated clinical abnormality, and their hearing impairment is referred to as nonsyndromic hereditary hearing impairment. Beginning in 1992, the location in the human genome of over forty different genes related to

nonsyndromic hearing impairment has been reported. Many of these advances resulted from extramural NIDCD support coupled with research efforts in NIDCD Intramural laboratories.

Within the last two years, great progress has been made in bridging the gap between determining the location of a gene involved in nonsyndromic hereditary hearing impairment and using this knowledge to clone the gene. As of January 1999, eight genes have been cloned, six within the last year. The identity of genes where mutations cause hearing impairment has taught us much about the molecular processes that are essential for normal hearing. These genes encode proteins that serve many different functions, including the transport of molecules between cells, forming channels that transport molecules into and out of cells, gene regulation, and moving molecular "cargo" within cells. Mutations in one of these genes, connexin 26, appears to be responsible for as much as forty percent of hereditary hearing impairment in the United States, and an even greater percentage in certain population subgroups.

With some of the genes in hand and more on the way, scientists and clinicians are turning their attention to unraveling the genetic epidemiology of hereditary hearing impairment. A number of important questions are being addressed using these new research tools, including: what fraction of the cases of hereditary hearing impairment result from mutations in each of the eight genes? In different families transmitting the same hereditary hearing impairment gene, is the same mutation in the gene found, or are there different mutations in different families? Does the type of mutation inform us about the onset or severity of hearing impairment? What are the differences in the genetic epidemiology of hereditary hearing impairment in different population groups, or in different parts of the world? Answers to these questions will play an important role in guiding clinicians and scientists in their efforts to translate these scientific advances into genetic diagnostic tests to provide a precise genetic diagnosis soon after birth, leading to early and appropriate intervention strategies to optimize language skills.

NEUROIMAGING REVEALS BRAIN ACTIVITY ASSOCIATED WITH LANGUAGE

The development of sophisticated neuroimaging techniques has allowed researchers to monitor brain activity patterns associated with perception and production of language, both spoken and signed. For example, functional magnetic resonance imaging (fMRI) findings suggest that delayed acquisition of language leads to anomalous patterns of brain activity when language is ultimately acquired. Using fMRI, NIDCD-supported investigators have documented reorganization of brain activity following treatment for acquired reading disorders following stroke. fMRI performed during a reading task before and after treatment indicated a shift in brain activation from the left angular gyrus to the left lingual gyrus, showing that it is possible to alter brain activity patterns with therapy for acquired language disorders. Continued investigations of normal and disordered language processes using neuroimaging tools will refine our understanding of brain function, improve our ability to identify the underlying causes of language impairment, and to document and refine the efficacy of interventions. Neuroimaging studies have had, and most certainly will continue to have, a profound impact on the study of language and language impairments.

PERSISTENT STUTTERING HAS A GENETIC ETIOLOGY

Stuttering is a speech disorder that typically begins in early childhood. Although it is estimated that more than two million Americans stutter, little is known about the cause of stuttering. At least five percent of children ages two to five are affected by stuttering. About twenty percent of these children develop chronic stuttering persisting into adult life, while the remaining eighty percent recover spontaneously. When stuttering persists, the disorder impairs verbal communication often resulting in difficulties with emotional and social adjustment. NIDCD supports research to develop methods to identify which young children are at high risk for persistent stuttering. This research has confirmed earlier research indicating that the tendency to stutter runs in families. Moreover, if persistent stuttering is observed in a child's family, the child is at increased risk for developing persistent stuttering. These findings help to inform clinicians about which children are more likely to have stuttering that persists into adult life, the group in greatest need of intense intervention.

SENSORINEURAL REGENERATION

Our sensory systems possess exquisite sensitivity, connecting us to our physical world and providing indispensable aids for daily life. Some of our sensory systems,

such as the senses of smell and taste, have the capacity to continuously replace sensory cells throughout adult life. The regenerative abilities of these sensory systems stand in sharp contrast to the limited potential for regeneration seen elsewhere in the adult nervous system. Studying the mechanisms that underlie sensory cell regeneration affords a unique opportunity to learn how to control and enhance neuronal regeneration at the cellular and molecular levels. Moreover, the information gained may translate into clinically useful information for regenerating neurons lost in the central nervous system following stroke, trauma, and neurodegenerative diseases.

Sensory systems show remarkable differences in the degree to which they are able to generate new sensory cells. In the mammalian hearing organ, the number of sensory hair cells is established early in development, and, following injury, are not replaced. In birds, by contrast, hair cell regeneration and restored auditory function is observed following injury. Scientists are examining the interaction between extracellular factors and molecules within the cell which determine whether or not a supporting cell in the inner ear can divide and generate a new hair cell. This regulatory process is fundamental to growth regulation in all organ systems, and is called cell cycle regulation.

NIDCD-supported scientists have examined the importance of one cell cycle regulatory protein, cyclin-dependent kinase inhibitor 27 (p27Kip1), an enzyme shown to regulate cellular proliferation by interrupting the cell cycle in other model systems. During development of the organ of Corti, as cells undergo terminal differentiation to become hair cells, they no longer express p27Kip1. By contrast, supporting cells, which are potential hair cell precursors, continue to express this enzyme. In mice where scientists have inactivated the p27Kip1 gene, there is an increased number of hair cells and supporting cells in the developing cochlea, and hair cells continue to differentiate from proliferating supporting cells in postnatal animals and adults. In contrast, normal mice with a functional p27Kip1 gene show no increases in hair cell number and no new hair cells are produced after birth. These exciting results demonstrate for the first time that hair cell regeneration is possible in mammals, and that cell cycle regulation is important in controlling hair cell regeneration.

In contrast to hair cells in the mammalian inner ear, olfactory sensory neurons are continuously replaced from a stem cell population in the nasal epithelium and the new neurons regrow axons that connect only to appropriate targets in the brain. NIDCD supported scientists have shown that olfactory neuronal regeneration is regulated by the production of a secreted growth regulatory molecule called bone morphogenetic protein 4. Knowledge gained from studying regulation of regeneration of olfactory neurons may provide insight into the more general issue of neuronal regeneration in the brain.

OLFACTORY RECEPTORS PROTEINS HAVE A DUAL FUNCTION

Researchers estimate that about 1,000 genes, or approximately 1 percent of our genetic information, is devoted to olfactory receptor genes, making this among the largest gene families thus far identified in mammals. These genes encode the proteins that bind odorants, which trigger a cascade of events within the olfactory neuron resulting in a signal being sent to the brain. Scientists are beginning to understand how olfactory signals are processed in the central nervous system. Each of the millions of olfactory neurons selects only one of this large receptor gene family for expression. All olfactory neurons expressing the same receptor send these axons to the same targets in the brain. An NIDCD-supported scientist has determined molecular mechanisms that regulate this remarkable targeting specificity by showing that the olfactory receptor protein itself appears to play a role in guiding axons to precise targets within the brain. The olfactory receptor expressed by a sensory neuron would appear to provide an address that guides the growing axon to a defined target. Genetic manipulation of the receptor that is expressed results in a new address and a different pattern of connections. These studies reveal a new molecular mechanism for determining connections between neurons in the nervous system, which may play an important role in the development of the central nervous system.

The activities of the National Institute on Deafness and Other Communication Disorders are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks for-

ward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. STEVEN E. HYMAN

Mr. Chairman and members of the Committee: I am pleased to present the President's budget request for the National Institute of Mental Health (NIMH) for fiscal year 2000, a sum of $758.9 million, an increase of $17.8 million (or 2.4 percent) above the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support proposed for NIMH is $876 million, an increase of $20.5 million over the fiscal year 1999 appropriation. Funds for NIMH efforts in AIDS research are included with the Office of AIDS Research budget request.

OBJECTIVES OF NIMH RESEARCH

The central goals of the NIMH are to better understand, treat, and, ultimately, to prevent mental illness. To succeed in this task, we must understand how the healthy brain works and how it goes awry to produce mental disorders. Achieving an understanding of the brain, the most complex object of all human inquiry, requires a substantial investment in fundamental science—specifically neuroscience, behavioral science, and genetics. Our mission also requires that we translate the fruits of basic science into the focus of clinical studies and into trials of both treatment and preventive interventions. Finally, we must investigate how these might best be implemented in the real world. Understanding disorders of the most complex, integrative functions of our brain is a difficult task that requires our Nation's very best scientific minds and a solid platform for our endeavors. I am pleased to report our progress in these areas.

REVIEW AND REORGANIZATION OF INITIAL REVIEW GROUPS

Over the past two years, NIH has been working to integrate the peer review groups, or study sections, that review grant applications. This effort was prompted by the merger into NIH of the institutes that formerly were components of the Alcohol, Drug, and Mental Health Administration. We and several other institutes proposed that all of NIH science would benefit if we began to review neuroscience, behavioral science, and AIDS-related applications in a wholly new set of study sections designed to reflect the science of the present and the future rather than the science of the past. With many extramural investigators assisting, NIH last year completed reorganizing neuroscience and AIDS-related study sections and, more recently, behavioral science study sections. The first round of review in our new neuroscience study sections went more smoothly than one might have predicted. Applications that were referred to the NIMH for potential funding received superb scores, and NIMH staff confirm that we are seeing appropriate and outstanding applications in neuroscience. We look forward to seeing the results of the other integrations over the next year.

REVITALIZATION OF RESEARCH STRUCTURE

We are rejuvenating our Intramural Research Program, raising standards and tightening procedures; given these tasks, I am fortunate to have had the opportunity to appoint a renowned scientist and natural leader, Dr. Robert Desimone, to direct our Intramural Research Program. In a development that bodes extremely well for the future of intramural neuroscience research and clinical neuroscience at the NIH, we have embarked on a period of remarkable cooperation with the National Institute of Neurological and Disorders and Stroke (NINDS). Our joint efforts are aimed at complementary and synergistic recruitments and renewal of facilities to recruit the most outstanding young scientists to the intramural program.

Finally, we have reorganized the NIMH funding divisions that provide grant funds to extramural scientists. I am confident that the reinvigorated intellectual excitement of our staff will translate into more and better applications to NIMH.

GLOBAL BURDEN OF ILLNESS SPURS COLLABORATIONS WITH WHO

My interest in recruiting the best scientists to a vigorous Institute is driven by the enormous, burden of mental disorders. I have spoken to you in the past about the Global Burden of Disease study, sponsored by the World Health Organization and World Bank. It is chastening to recall that in the United States, four of the ten leading causes of disability are mental disorders, including the number one cause, major depression. Depression now is the leading cause of disability throughout the world; even when listed among traditional "killer" diseases, it ranks fourth

and is projected soon to become the world's second leading cause of disability-adjusted life years, or DALYs. You may have seen the recent New York Times account of a "plague" of suicides among women in rural China, where the rate is fivefold that found in other nations. The fact that some officials dispute the contribution of mental disorders to this public health emergency adds urgency to our various international research initiatives. We are working, for example, with other countries to evaluate the usefulness of screening for and treating depression in primary care settings. Also, in collaboration with WHO, NIMH assumed a lead role at NIH in developing a new "disablement" instrument. This new tool will permit WHO to measure more accurately the functional status of people with mental and substance abuse disorders and, thus, sharpen its disability calculations—a critical ability, in light of the obvious limitations of judging a population's health on the basis of mortality statistics alone. Now, let me describe specific NIMH scientific plans and accomplishments, beginning with short-term and progressing to long-term goals.

COMBATING SCHOOL VIOLENCE

An immediate goal is to see the yield of research sponsored by NIMH and other agencies translated into useful interventions. Over the past year, our Nation's attention was caught by unprecedented incidents of violence in schools—the tragedies in Jonesboro (AR), Paducah (KY), Edinboro (PA), Springfield (OR), Pearl (MS), and Burlington (WI). NIMH is collaborating with the Department of Education's Safe and Drug Free Schools program; with the Department of Justice, Office of Juvenile Justice and Delinquency Prevention; and with the Center for Mental Health Services, to transfer knowledge about appropriate interventions for troubled youth.

Our research shows that symptoms of mood and anxiety disorders, attention-deficit/hyperactivity disorder, and conduct disorders derail children from their normal developmental trajectory, impair learning, are risk factors for adult psychopathology, and contribute to the high rate of suicide among our youth and to violence. By working with other agencies—for example, by building on our history of collaborations with Head Start and other components of the Administration for Children and Families—we want to ensure that potentially useful research results get tested in real world settings and, if proven effective and cost-effective, are used where they can do some good.

EXPANDED CLINICAL TRIALS FOR MENTAL ILLNESS

In the intermediate term, we must apply information gained from basic research into rigorous, prospective trials of the efficacy and general effectiveness of treatments. NIMH has not, in its recent history, supported a substantial clinical trials program. I am pleased to report that we now have initiated clinical trial contracts to study the treatment of manic depressive illness, pediatric depression, and treatment-resistant depression, and are considering how best to go about preventive and early intervention trials for depression and for psychotic disorders. The first trial initiated in this program—our collaboration with the NIH National Center for Complementary and Alternative Medicine to evaluate the herbal, St. John's Wort, in treating depression—is underway.

GENETICS RESEARCH AT NIMH

With regard to longer term scientific directions, we now have a comprehensive strategy for discovering the genes that confer vulnerability to schizophrenia, manic-depressive illness, depression, autism, and other mental disorders. These disorders reflect the workings not of single, powerful, readily detectable genes, but rather the small contributions of many genes and non-genetic factors. Finding these "needles in a haystack" is critical because they will be central tools as we interrogate the brain as to what goes on in mental disorders and work to develop novel therapies. Key to our success will be an effort to collect DNA and phenotype information from affected families and assist NIH to develop technologies to solve genetically complex disorders.

Like others at NIH, we are relying on the Human Genome Project to produce a reference human sequence. At the same time, we and other neuroscience institutes are contributing to other aspects of the technological platform for genetics studies. Initially with NINDS—and now with other neuroscience institutes as well—we have launched the Brain Molecular Anatomy Project, or BMAP. This is an attempt, initially in the mouse but ultimately in the human, to discover all of the genes involved in building and maintaining the brain. Information from the BMAP project will be fed into studies trying to find human genetic variation. These will be our best candidates for genes that contribute to vulnerability of mental illness.

The analysis of genetic variations and their relationships to disease will require additional technologies. One important technology—the ability to score many genetic variants on what have been called "DNA chips"—is being supported both extramurally and by a shared NIH intramural effort. In addition, NIMH has the lead in a successful NIH-wide Request for Applications to develop novel statistical and mathematical methods to analyze the extraordinary complexity of the results.

Finally, we are closely involved with six other neuroscience-funding institutes to develop programs using model organisms, most notably the laboratory mouse, to understand how the brain is built and maintained, how it changes over the life span, and what might contribute to behavioral disorders. This effort will require collaborations among behavioral scientists, neuroscientists, and geneticists, and will provide rich possibilities for the future. During the past year, for example, NIMH funded research on mouse models has provided insight into fundamental processes of learning and memory. Understanding how the brain stores information and converts it to behavior is key to understanding complex mental disorders. NIMH-sponsored scientists recently reported using gene knock out techniques to examine the link between a behavior and the responsible molecular reactions in specific brain cells by demonstrating the role of an enzyme—protein kinase C, or PKC—in motor memory and coordination. Their success will lead to further studies examining the function of genes thought to be functionally important in normal brains, psychiatric illness, and neuronal disease.

CHILDREN'S MENTAL DISORDERS

One other set of important, long-term plans is our effort to build the field of children's mental health research. As I have testified previously, I am concerned over the dearth of qualified investigators in this arena. NIMH now has issued a special Request for Applications to create incentives for experienced investigators to move into studies of mental illness in children. We have created two funding branches devoted to children: Developmental Psychopathology and Children's Treatment and Preventive Interventions. In basic science, we are collaborating with NINDS as we focus in focus on developmental neurobiology. We also are emphasizing efforts to develop better screening tools and epidemiologic methods that will help us to understand exactly what is the burden of mental illness and, more generally, of emotional symptomatology for our Nation's youth, its impact, and its relationship to service availability.

NIMH was the lead organizer of a recent NIH Consensus Development Conference on Attention-Deficit/Hyperactivity Disorder, or ADHD. The meeting highlighted useful information for parents and treatment professionals, but for me, it more importantly produced a mandate for better diagnostic approaches to ADHD, better documentation of the long-term impact of stimulant drugs on children with ADHD, and development of alternative behavioral and pharmacologic treatments. Similar needs characterize other childhood disorders—for example, disorders of mood and anxiety and autism, for which four NIH institutes share scientific responsibility.

This drive toward the future is paved by current successes, such as that seen in the recently reported Multimodal Trial of Treatment for Attention Deficit Hyperactivity Disorder. The MTA evaluated four treatment conditions—medication with supportive care, behavioral treatment, combined, or "usual" community treatment. Findings from nearly 600 kids, followed over 14 months, pointed to the superiority of appropriately managed medication strategies in treating core ADHD symptoms or medication plus behavioral treatments for also addressing non-ADHD-symptom areas such as social skills or academic achievement. It will be important to examine long-term outcomes. NIMH has funded to date 7 Research Units in Pediatric Psychopharmacology, 1 new Child and Adolescent Development and Psychopathology Treatment Center, and launched several new multisite clinical trials, including, last year studies of treatments for children with schizophrenia, manic-depressive illness, depression, and OCD.

The activities of the NIMH are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. ALAN I. LESHNER

I am pleased to present the President's budget request for the National Institute on Drug Abuse for fiscal year 2000, a sum of $429.2 million, an increase of $10.3 million (2.4 percent) above the fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support provided for NIDA is $622.8 million an increase of $14.6 million over the fiscal year 1999 appropriation. Funds for NIDA efforts in AIDS research are included within the Office of AIDS Research budget request.

NIDA has had another very successful year filled with major scientific advances that are directly benefitting the citizens of this Nation. Among other benefits these advances have given us an opportunity to embark on a course that is certain to enhance drug addiction treatment throughout this country. Recent advances in treatment research, coupled with the generous appropriations that NIDA received last fiscal year, are enabling the Institute to accelerate the launch of its much-anticipated and needed National Drug Abuse Treatment Clinical Trials Network. This Network will serve as both the infrastructure for testing science-based treatments in diverse patient and treatment settings and the mechanism for promoting the rapid translation of new science-based treatment components into practice. I will return to this issue shortly, but first would like to mention some other significant discoveries and advances that are affecting our approach to addiction research.

The use of the most modern technologies, developed through the combined efforts of many NIH Institutes, is revolutionizing our approaches and understanding of the processes of drug abuse and addiction. Two technologies in particular—molecular genetics and brain imaging—are quickening the pace of science and allowing us to pose a whole new series of sophisticated questions that were unimaginable just a few years ago.

MOLECULAR GENETIC TECHNIQUES

When I became the NIDA Director five years ago, I reported what then was a milestone in drug abuse research that our researchers had identified and cloned the major receptors for virtually every drug of abuse. Today, I am equally pleased to report that the application of molecular genetic technologies has taken our understanding to the next level by giving us a greater understanding of how drugs work at these receptors and how these mechanisms impact behavior and other brain functions. In the past few years this technology has resulted in the development of new strains of genetically altered, "knockout" mice, which lack one or more of these receptors. Studies of the drug-responsiveness and behavioral characteristics of these mice are illuminating both the complexity and the inter-connectedness of the brain mechanisms that underlie individual drugs of abuse. Earlier this year NIDA-supported researchers used these knockouts to discover that some of the properties of opiate drugs such as heroin or morphine that lead people to abuse them are actually dependent upon the presence of the brain's natural receptors for cannabinoids, or marijuana-like drugs. Moreover, we are seeing increasing evidence that there are common brain mechanisms subsuming the phenomenon of addiction, regardless of the type of drug being used.

Information from these types of studies are also charting us in new directions. For example, they are pointing us to new targets in our medications development program. They are also proving to be invaluable to NIDA as it continues its "Vulnerability to Addiction" Initiative. This multi-faceted initiative to identify the genetic and environmental factors that contribute to individual differences among people in their addiction vulnerability will improve diagnosis, prevention, and treatment of drug addiction.

A prime example of the applicability of basic genetics research to the real life problem of addiction was reported at our "Addicted to Nicotine" Conference. Researchers identified a gene variant for a liver enzyme that seems to predict, at least in part, individuals who are more or less likely to become dependent upon nicotine. This finding gives us a new target for developing more effective medications to help people stop smoking. Another major output from that conference was the announcement of co-support by the National Cancer Institute and NIDA to establish collaborative Transdisciplinary Tobacco Research Centers. The Centers will bring together researchers from different scientific disciplines to answer pressing questions, such as: Why do children start smoking? How can people be helped to quit smoking? And, what are the genes that predispose people to tobacco addiction?

DRUGS AND THEIR LONG LASTING EFFECTS ON THE BRAIN

Genetic techniques are one of many tools being used by scientists to expand our understanding of addiction. Neuroimaging is another. Use of the most advanced neuroimaging technologies is providing tremendous insights into what happens to brain structure and function in awake, behaving human beings both during drug experiences and over the course of their addictions.

We are now clearly seeing the long lasting effects that drugs can have on the brain and how these may have lasting effects on an individual's emotional responses and on his or her learning and memory capacity. For example, MDMA or "Ecstasy" and methamphetamine are both becoming increasingly popular with young adults who attend organized all night social gatherings or "raves." Based on animal studies both drugs have long been thought to be neurotoxic at doses similar to what is being used by these young adults, but direct evidence in humans was lacking. Now let me show you some alarming recent data.

Figure 1 shows images of two human brains. The one on top belongs to an individual who has never used Ecstasy. The bottom images show the brain of an individual who had used Ecstasy heavily for an extended period, but was abstinent from drugs for at least three weeks prior to the study. Clearly the brain of the "Ecstasy" user on the bottom has been significantly altered. The specific parameter being measured is the brain's ability to bind the chemical neurotransmitter serotonin. Serotonin is critical to normal experiences of mood, emotion, pain, and a wide variety of other behaviors. On the figure, brighter colors reflect greater serotonin transporter binding; dull colors mean less binding capacity. This figure shows a decrease in the Ecstacy user's ability to remove this important neurotransmitter from the intracellular space, thereby amplifying its effects within the brain. This decrease lasts at least three weeks after the individual has stopped using Ecstacy. Given serotonin's critical role in many behavioral characteristics, one can speculate that this abnormality of the serotonin system might be responsible for some of Ecstasy's long-lasting behavioral effects.

Figure 2 also demonstrates the long-lasting effects that drugs can have on the brain. Here you can see dopamine transporter binding in four different adults. Brighter colors reflect greater dopamine binding capacity. The scan on the left is that of a non-drug user, the next is of a chronic methamphetamine user who was drug free for about three years when this image was taken, followed by a chronic methcathinone abuser who was also drug free for about three years. The last image is of the brain of an individual newly diagnosed with Parkinson's Disease. When compared with the control on the left, one can see the significant loss in the brain's ability to transport dopamine back into brain cells. Dopamine function is critical to emotional regulation, is involved in the normal experience of pleasure and is involved in controlling an individual's motor function. Thus, this long-lasting impairment in dopamine function might account for some of the behavioral dysfunctions that persist after long-term methamphetamine use.

The application of these technologies is not only illuminating long-standing issues in our field but actually redirecting our overall approaches. For example, these and other brain imaging studies suggest we need to be looking into totally different areas of the brain than those traditionally pursued. We may find that behavioral components such as decision-making, impulse control, abstinence, craving and relapse are actually tied to some of these less explored regions. By expanding our exploration of the brain, at the molecular as well as more global levels, we will gain greater insight into all areas of the brain. All of these insights have come about because we have these new technologies. But to continue the pace of science they need to be exploited even more.

NATIONAL TREATMENT IMPROVEMENT

A recent study supported by NIDA and the National Institute on Alcohol Abuse and Alcoholism estimates that drug abuse and addiction cost the American public more than $110 billion per year, and improving drug use prevention and treatment are the principal vehicles to reduce those costs. All of the advances I have mentioned so far have helped bring us to a point where we now have a strong scientific base to more systematically approach how we treat people with addictions. Just like with other illnesses, drug abuse professionals have at their disposal an array of quite useful tools to treat addicted individuals, and many of these tools have been supported by NIDA. We have developed readily available nicotine addiction therapies; we have brought to the world the most effective medications to date for heroin addiction; and we have standardized notable behavioral interventions, such as cognitive behavioral therapies and contingency management, that are effective in treating both adults and adolescents. However, there are a number of other promising

therapies that have not yet been tested on a large scale or in diverse patient populations. This is one of the many reasons why we are launching the National Drug Abuse Treatment Clinical Trials Network.

The establishment of this Network responds to a long-acknowledged need to use science to significantly improve drug abuse treatment. Building this Network is a major priority for the drug abuse field and was the principal recommendation of the Institute of Medicine's recent report Bridging the Gap Between Practice and Research. The plan is to establish an infrastructure that will enable the field to more rapidly test and bring new science-based treatments into real life settings. The Network we are establishing is modeled after those used successfully by other NIH institutes. Through this network, university-based medical and research centers will form partnerships with community-based treatment providers to test and deliver an array of treatments, while simultaneously determining the conditions under which the novel treatments are most successfully adopted. NIDA plans to make four awards in the current fiscal year.

In a related effort to enhance treatment, NIDA's medications development program is taking the first promising anti-cocaine drug medications into multisite Phase III Clinical trials. These trials will evaluate two innovative routes of administration for the medication selegiline, in the form of a transdermal patch and as a time released pill, to determine which is most beneficial to the populations being studied. NIDA is also on the verge of bringing the Nation a new anti-opiate treatment, buprenorphine. One of the advantages of this medication is its ability to be administered in less traditional environments and brought into mainstream medical practice We expect to broaden treatment access to even more opiate addicts by having it available in office-based practices. Also in the treatment arena, NIDA will continue to aggressively pursue both an antidote and a medication to help with overdoses and addiction to the dangerous drug methamphetamine.

APPLYING THE PRINCIPLES OF PREVENTION RESEARCH

In the prevention arena, NIDA is entering what many would consider the next generation of drug prevention research. That is, taking the fundamental principles of effective drug abuse prevention programming to the next level so that they are effectively integrated into every community and social system in the country. Our research agenda will also reflect our commitment to have prevention interventions directed at the specific needs of different groups of youths at risk for drug abuse, including members of different ethnic groups and those living in different socioeconomic situations. Preventing all youth from initial drug use is not only the right thing to do, but is also economically responsible.

We will also continue to support research that prevents adults, especially women of child bearing years, from using drugs. NIDA research continues to find subtle cognitive effects in children born to mothers who abuse drugs like crack. This is especially disturbing in light of a recent analysis of studies that estimated that subtle deficits in IQ and language development will occur in up to 80,550 cocaine-exposed children each year. Although the developmental effects are subtle, special education to prevent these children from failing in the school environment could cost up to $352 million per year according to a 1998 Brown University analysis. Continued investments in prevention research will help to reduce this spiraling cost of drug use to society.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The activities of the NIDA are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

25 YEARS OF DISCOVERY

This year, NIDA celebrates twenty five years of progress in understanding, treating and preventing drug addiction. The world has seen many changes over this time period, including a reduced burden of disease for its citizenry, thanks in large part to our Nation's strong biomedical research enterprise. Addiction treatments for example have helped to not only reduce drug use but the spread of infectious diseases

such as HIV, while also diminishing the health and social costs that result from addiction, and decreasing criminal behavior.

We have a lot to be proud of, but we still have much more to accomplish. There is no better time than a 25th anniversary, to reflect on the profusion of knowledge gained since an organization's inception. It is also an ideal time to chart one's course for the future. A continued investment into our research will allow us to cultivate the kinds of activities needed to reduce the devastating consequences of drug abuse and addiction.

PREPARED STATEMENT OF ENOCH GORDIS, M.D.

Mr. Chairman and Members of the Committee: The fiscal year 2000 budget request for NIAAA is $248.9 million, excluding AIDS, an increase of $5.8 million or 2.4 percent over the current fiscal year 1999 amount. Including the estimated allocation for AIDS, total support proposed for NIAAA is $265.5 million, an increase of $6.2 million over the fiscal year 1999 appropriation. Funds for NIAAA AIDS research are included in the Office of AIDS research budget request. The total NIAAA budget request includes support for the following NIH Areas of Special Emphasis: biology of the brain, new preventive strategies against disease, development of therapeutics, and genetics of medicine.

The mission of the NIAAA is to improve, through its research, prevention and treatment of alcohol disorders and their enormous consequences. Among the nearly 14 million adult Americans who suffer from alcohol disorders, 100,000 die of alcohol-related causes each year, according to NIAAA epidemiology research and American Psychiatric Association diagnostic criteria, and to independent researchers published in #T3Scientific American, respectively. The NIAAA's epidemiology research reveals that more than four times#T3 that many, 442,000, spend time in acute-care hospitals. Of the estimated $166 billion that alcohol disorders cost society annually, more than $22 billion is attributable to health care and more than $119 billion to lost productivity, according to a study conducted by NIDA and NIAAA.

GENETICS

Since the risk of developing alcoholism is influenced about equally by genes and environmental factors, one of NIAAA's tasks is to identify the genes that are involved. The search has been a productive one. Investigators from the NIAAA-funded Collaborative Studies on the Genetics of Alcoholism, or "COGA," have identified four chromosomal regions likely to contain genes that influence alcohol-related behavior. NIAAA's intramural researchers independently identified one of the same regions and identified a fifth site. The task ahead is to identify the genes themselves, so that scientists may exploit the potential of this knowledge for more effective medication design and more targeted preventive interventions. Discovery of these chromosomal regions provides a crucial starting point for the search. In October, NIAAA will make COGA's powerful data set available to as wide a scientific audience as possible, to expedite the search for specific genes implicated in alcoholism.

Using tools of molecular biology, NIAAA-supported investigators demonstrated an association between a gene mutation in fruit flies and an alcohol-induced behavior. This research is a striking demonstration of how the study of lower organisms can help us understand human biology, and has garnered a Presidential Early Career Award for Scientists and Engineers for one of its investigators. Fruit flies have in common with humans chemical pathways essential to survival. In tracking one of these chemicals—"cAMP"—researchers found that flies with a genetic mutation that makes them more sensitive to alcohol also produce less cAMP than do genetically intact flies. As seen here, flies with this mutation lost their coordination on exposure to alcohol fumes more rapidly than did other flies. Giving these mutated flies substances that increased cAMP levels made them less sensitive to alcohol. These findings suggest a link between this gene mutation, production of cAMP, and an alcohol-related behavior. In the future, findings such as this will provide guidance in the search for new sites for interventions.

NEUROSCIENCE AND MEDICATION DEVELOPMENT

Because genes, proteins, molecular biology, and neuroscience are closely related, studies in any one of these areas serve to inform the others, and all of them are highly relevant to drinking behavior. For example, genes encode proteins that play crucial roles in chemical pathways that influence behavior. For some time, scientists have known that alcohol affects several neuroreceptors in the central nervous system. #T3How alcohol affects these receptors remains an important research ques-

tion. In an ingenious series of experiments, NIAAA-supported researchers substituted protein sections of these neuroreceptors with genetically engineered sections, one at a time. Through this process of elimination, they found the part of the receptor molecule that was indispensable to alcohol's action on the nerve cell. This type of research, in which investigators are beginning to examine intimate details of the structure of receptors, will serve as a guide to designing medications that counteract alcohol's effects, in the future.

The NIAAA's efforts include not only this important basic-science research, but also testing of existing new medications for their utility in treatment. Project COMBINE, a large NIAAA-funded clinical trial, is testing two medications, naltrexone and acamprosate, that represent a new generation of pharmaceuticals for the treatment of alcoholism. These medications act directly on pathways thought to be important components of addiction by blocking rewarding sensations associated with alcohol or blocking aversive effects of abstinence, respectively. Both medications are being tested alone and in combination with behavioral therapies refined from results of Project MATCH, a previous NIAAA-supported clinical trial that compared outcomes of various behavioral treatments. NIAAA neuroscience research provides the type of information that, after testing for safety and efficacy in the laboratory and in small-scale human trials, then large-scale clinical trials, may result in medications with clinical utility.

PREVENTION

Just as careful, controlled trials are needed for medication development, they are equally necessary for proving the effectiveness of prevention efforts. The NIAAA has an extensive prevention portfolio that addresses a variety of topics, such as drunk driving and underage drinking, that are in various stages of investigation. Alcohol use among youth is a major area of concern at the Institute. Preventing young people from developing alcohol disorders is, of course, preferable to treating them. The NIAAA and CSAP are cofunding research to determine effects of alcohol advertising on initiation and continuation of drinking among youth. Recently, the Surgeon General introduced an initiative aimed at preventing underage drinking. The NIAAA is the leading contributor to this new effort.

College-age drinking is a difficult and widely publicized problem, and one that receives special emphasis in NIAAA's research. An example of a recent finding in this area is described in this poster, which summarizes data from one of the few randomized, controlled trials conducted in this population to date. Previously, we had informed the Committee that a brief, one-time session that corrected high-risk college students' expectations about how much their peers drank appeared to reduce these students' drinking and alcohol-related problems. The recently published results of this trial support that assertion. As this 2-year follow-up graph indicates, high-risk students who received the intervention declined in their rates of drinking and harmful consequences significantly more than did high-risk students who received no intervention. This excellent study is a rare example of interventions that have been evaluated in this manner. Research has yielded several promising remedies that await similar—and necessary—rigorous testing, and additional investigations are underway. The Institute's National Advisory Council also has formed a subcommittee on college-age drinking, cochaired by the president of the University of Notre Dame and an eminent alcohol researcher. Ten college presidents and 12 leading researchers comprise this subcommittee. After assessing the entire college-drinking area, this subcommittee will advise the Institute about productive research avenues.

NIAAA epidemiology data dramatically revealed that earlier age of drinking onset is associated with increased likelihood of lifetime alcohol dependence. The reasons for this phenomenon are now subject to investigation. On one hand, it is possible that neurobiological changes in the adolescent brain are related to this increased risk; on the other hand, various psychosocial factors may be involved. Results from research in this key area will add to scientists' understanding of how alcoholism develops and will provide direction in the search for effective interventions.

FETAL ALCOHOL SYNDROME

Fetal alcohol syndrome (FAS) remains the leading cause of preventable birth defects in the United States, and the NIAAA is approaching this issue from a variety of angles. In animal studies, scientists are identifying biological changes that occur in embryos exposed to alcohol. Of particular interest is the neural crest, a group of embryonic cells that later develop into cells of the brain and spinal cord, among other structures. The timing of developmental events that occur in neural crest cells is critical, and the changes that alcohol causes in them are now being related to

FAS. Researchers also have established that a class of molecules called free radicals, which are generated by alcohol and other substances, damage neural crest cells and that antioxidants mitigate that damage. Diagnosis of FAS at birth by physical characteristics is difficult; investigators therefore are searching for a surrogate chemical indicator, suitable for clinical diagnosis, of fetal damage induced by alcohol. NIAAA-supported scientists have identified a potential biomarker, an elevated level of a protein, that may lead to methods of prenatal diagnosis of FAS and, thus, early intervention.

One of the Institute's tasks is to prevent FAS more efficiently, especially by reaching women who have not had access to the message that alcohol damages unborn children. The NIAAA currently is conducting large-scale research on how to prevent alcohol use among pregnant women and is stimulating further research on this topic.

OUTREACH

In addition to its ongoing efforts to disseminate information, the Institute is engaged in several special projects aimed at raising public awareness and improving clinicians' skills in dealing with patients who have alcohol disorders. One of these projects is a curriculum that enables medical schools to integrate information on alcohol disorders into their programs. This substantial curriculum, shown here, is entitled A Medical Education Model for the Prevention and Treatment of Alcohol Use Disorders. Too often, health practitioners have received little training in how to diagnose and treat their patients' alcohol problems, and increasingly busy health practitioners sometimes do not adequately address them. This omission has significant medical and social consequences. The curriculum shown here enables students and physicians to recognize alcohol-related problems and to intervene more efficiently and productively. Ultimately, patients are the beneficiaries of this valuable resource.

One of the Institute's goals is to translate findings from alcohol research into applications that can be implemented in a variety of clinical settings. In response to requests from State officials and others, the Institute held its first Research-to-Practice Forum in New York, in partnership with the State and with other Federal and national organizations. During this NIAAA-led meeting, scientists, administrators, and providers discussed methods of incorporating current research findings on alcohol disorders into clinical practice. Another forum will be held in North Carolina in November, and the State of Hawaii has requested a similar event, to be held in March.

Although alcohol is a highly prevalent disorder in our society, only a fraction of the people who would benefit from treatment are getting the help they need. To increase the number of people who can improve their lives through treatment and avoid the disastrous consequences of drinking, the Institute is embarking on a new project: National Alcohol Screening Day. The first will take place in communities across the country on April 8. This event is being offered by the NIAAA in partnership with the National Mental Illness Screening Project and will offer free screening and referral services to anyone who asks for them. It will also educate the public about alcohol disorders. The Institute's goal is to enlist 2,000 sites, 650 college campuses among them, that will offer these services. Several private organizations have joined the NIAAA, which is the major funder of the event, in supporting National Alcohol Screening Day. An additional 19 prominent national organizations have endorsed it.

A partnership between the NIAAA and the Kettering Foundation promises to raise the Nation's awareness of alcohol disorders and their consequences. For the past 16 years, the Foundation has chosen a topic of public interest and has sponsored community discussions throughout the Nation. The topic for this year's National Issues Forums is alcohol use and the public's attitude toward alcoholism. The goal of the Forums is to help an informed public take an active role in policy decisions. At the National Press Club, Forum representatives will summarize, for the media, the outcome of the national discussions and will describe the direction the citizenry has taken on alcohol issues. A PBS presentation will be the final event in this valuable effort.

SUMMARY

Alcoholism is a complex disease, not only because it is influenced by several genes and by multiple biological interactions, but also because it is influenced by many other factors, such as family and social environment. The NIAAA maintains a research portfolio that balances these complex issues. We will continue to identify the biological mechanisms that predispose people to alcohol disorders and to develop methods of altering those mechanisms. At the same time, we recognize that behav-

ioral interventions can prevent people from engaging in activities that trigger biological mechanisms involved in alcoholism, and our portfolio reflects that understanding, as well. All of this research is occurring in the context of collaborations with public and private partners and of outreach to the people to whom it matters most: those at risk of suffering from alcohol disorders or those at risk of suffering the consequences of someone else's abuse of alcohol—and that represents all of us. The activities of the NIAAA are covered within the NIH-wide Annual Performance Plan required under the government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan, which was transmitted to Congress on September 30, 1997. The NIH performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change, based on final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. PATRICIA A. GRADY

Mr. Chairman and Members of the Committee: The President in his fiscal year 2000 budget has proposed that the National Institute of Nursing Research (NINR) receive $65.3 million, an increase of $1.5 million over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support provided for NINR is $71.73 million, an increase of $1.7 million over the fiscal year 1999 appropriation. Funds for NINR efforts in AIDS research are included within the Office of AIDS Research budget request.

NINR-supported nursing research provides a scientific base for patient care and is used by many disciplines among healthcare professionals—especially by the nation's 2.5 million nurses. NINR-supported research is not disease specific, nor is it dedicated to a particular age group or population. Nursing research addresses the issues that examine the core of patients' and families' personal encounters with illness, treatment, and disease prevention. NINR's primary activity is clinical research, and most of the studies we support directly involve patients. The basic science we support is linked to patient problems.

Nursing researchers are essential in defining and confronting the compelling health challenges of the 21st century. These challenges will reshape not only health research and health care, but the way Americans view the importance of good health in their lives. Nursing research is developing creative solutions to address these challenges. I will now describe some of these nursing research initiatives and their relevance to the present and future health of the nation.

CHRONIC ILLNESS—A COMPLEX CHALLENGE

The increase in chronic illnesses results from the increase in the aging of the population and technological advances that transform acute illness into chronic illness, such as AIDS and heart disease. Chronic diseases in turn have created complex challenges for the health care system as it attempts to respond to the needs of frail patients with multiple diseases, some of whom are at end of life. Furthermore, the help that family members require in managing their burden of care has become a major issue in health and social policy. Nursing research has developed a number of innovative scientific projects to address the concerns of caregivers at home, as well as programs designed to ease the symptoms of chronic illness and prolong quality of life.

A recent study has shown how a transitional care model can improve the health of older adult patients with common medical and surgical problems. This study used a multidisciplinary approach to assess care needs and included follow-up in the home delivered by expert nurses. Nurse experts used their clinical judgment to determine the nature, intensity and frequency of hospital and home care visits for their patients. Reduction of hospital re-admissions for high risk older adults with complex treatment regimens, reduced length of hospital stay and reduced costs to the health care system were among the study findings. The investigator is now applying the transitional care model specifically to older adults with congestive heart failure, a condition which carries poor prognosis and high hospitalization rates for all adult patients.

Another research advance reveals that estrogen limits damage to brain tissue from ischemic stroke or brain attack. In studies using an animal model for human ischemic stroke, investigators found that females with natural or injected estrogen experienced only about one-third as much brain damage as males. These finding are

complementary to the findings in humans that estrogen exercises a protective effect for women against coronary heart disease. Researchers also tested whether estrogen could have the same protective effect in male animals. Estrogen did in fact provide a significant reduction of brain damage after acute stroke in the male animals. Furthermore, the presence or absence of testosterone did not affect the favorable outcome. This basic research has important findings for future clinical investigations.

NINR's focus on chronic illness will provide a new emphasis in fiscal year 2000 on symptom management of children with asthma. The death rate for asthma has doubled since 1980 among children 5 to 14 years of age. NINR-supported research will test nursing interventions to decrease the severity and frequency of asthma attacks, monitor airway inflammation, and manage daily care.

HEALTH DISPARITIES

In keeping with its important theme of individualizing care, NINR continues to refine interventions that are responsive to age, gender, cultural identity, and socioeconomic environments. Nurse researchers are especially conscious of the current demographic trends that point to disparities in access to and utilization of health care services by Hispanic, African-American, and Asian ethnic groups. NINR is committed to supporting research that will address these disparities as a significant public health problem.

An NINR-funded study showed that interventions have reduced high blood pressure in inner city young African-American males. In this study, an intervention was directed at this particularly hard-to-reach population which has the lowest rate of awareness, treatment and control of high blood pressure of any population group in the United States. At the two-year study's mid-point, blood pressure control increased in the young men in the intervention group and numbers of emergency room visits decreased.

NINR will continue to expand its research support next year in the area of health disparities by examining the problem of low birth weight in minorities. The incidence of low birth weight disproportionately affects minorities and requires culturally sensitive approaches and interventions to improve birth weight at delivery. We will identify changing risk factors and will continue to develop and test effective pre-and post-natal care interventions based on new research results.

HEALTH PROMOTION AND DISEASE PREVENTION RESEARCH

NINR is improving health and preventing disease. The Cardiovascular Health in Children (CHIC) project demonstrated that an eight-week education and exercise intervention conducted in rural and urban elementary schools across North Carolina significantly reduced risk factors for cardiovascular disease in pre-adolescents. Their cholesterol levels and body fat were reduced, aerobic power was increased, and diastolic blood pressure did not rise as much as in the control group. The investigator expanded the study and is now testing the intervention in 1,200 rural, ethnically diverse 6th through 8th graders. Preliminary results from this expanded study indicate similar benefits. The study suggests that providing the program throughout the nation for longer periods of time could decrease the high incidence of cardiovascular disease.

NINR-supported research indicates that "coping skills training," which involves role-playing in difficult social situations increases the control of diabetes in young adults. We know that intensive diabetes therapy reduces complications in adolescents, although young people tend to be the most difficult age group to manage for diabetes. Findings show that they know what to do, but peer pressure is hard to resist, and they eat unwisely and do not balance exercise with appropriate blood sugar levels. After a three-month intervention test period, findings indicate that members of the intervention group had consistently lower glucose levels and were confident that they could manage their disease as they went about their typical adolescent lives. This short term study has promise of long term benefits for teens, who otherwise have poorer diabetic control than adults.

NINR plans to enhance the emphasis on diabetes research in fiscal year 2000 by looking at diabetes self-management strategies that include cultural, ethnic, and age-related factors. NINR will also identify ways to facilitate adherence to regimens that require close adjustments in medication and food intake.

QUALITY OF CARE AND QUALITY OF LIFE

NINR has been designated as the lead Institute to coordinate research on end-of-life palliative care, and is committed to improve how health care professionals interact with those who are dying. Through scientific research, we shall focus on patients at the end of life so that they receive compassionate and life-affirming health

care. Health care professionals must make a difficult choice on the continuum between cure-oriented treatments or comfort-oriented palliative care. Currently there is a tendency to use all means to extend life, regardless of the patient's comfort or, in many cases, expressed wishes. The findings from NINR's research portfolio have contributed much to palliative care, especially in symptom management of pain and other physical stressors, such as nausea, shortness of breath, and profound weight loss. Research on caregiver training and support is another critical area. Bioethical issues and the decision-making processes of patients, their families, and clinicians, including procedures to guide treatment options and palliative care, are also part of the nursing research agenda. Recently, researchers found that according to family reports, clinicians underestimate the level of pain and other physical distress of dying patients. Research will facilitate more options and better use of resources, such as by delaying or avoiding expensive hospitalization for symptoms that could have been managed by hospice or home-health nurses. Clearly, changes based on scientific evidence are essential, and NINR is pleased to have a central role in addressing this major health care challenge.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The activities of NINR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. FRANCIS S. COLLINS

Mr. Chairman, and members of the Committee: I present here the President's budget request for the National Human Genome Research Institute (NHGRI) for fiscal year 2000, a sum of $271 million, an increase of $6 million (or 2.4 percent) above the fiscal year 1999 comparable level. Including the estimated allocation for AIDS, total funding proposed for NHGRI is $276 million. Funds for NHGRI efforts in AIDS research are included in the Office of AIDS Research budget request.

GENOME SEQUENCING AT THE FOREFRONT

For the first time, in December 1998, an international team of scientists, supported by NHGRI and the Medical Research Council of Great Britain, published the complete genome sequence of a multi-cellular animal, the tiny roundworm Caenorhabditis elegans. At 97 million DNA bases and over 19,000 genes, its genome is the largest and most similar to humans of any sequenced thus far. All of the worm sequence data is freely accessible. Although it is barely visible, C. elegans contains many of the same body systems as humans, which can now be studied in entirely new ways. New genomic studies of the worm promise to shed light on cancer, birth defects, aging, and neurological disorders. About 80 percent of the genes that have been implicated in human illness have counterparts in the worm. Science magazine hailed the completion of the C. elegans sequence as one of the 10 most important scientific discoveries of the year.

Success in completing the worm genome sequence and the loud clamor from the scientific community for more sequence from many organisms compelled genome project leaders last fall to move up the deadline for completing the human genome sequence to 2003. The technology to do so is at hand. Indeed, as of early 1999, the public sequence database contained over 400 million bases of precisely mapped finished and nearly finished human genome sequence. This amounts to 13 percent of the total 3 billion. In addition to the plan's bold new proposal for finishing a complete, highly accurate human genome sequence in 2003, it also promises to deliver a "working draft" of the sequence by the end of 2001. Though that sequence will be of lower quality, it will nevertheless be very useful for finding genes and other genomic features, which will result in significant time and cost savings for a large number of scientific projects. Because more than half of the genes are predicted to lie in the gene-rich third of the genome, the finishing effort during the next three years will focus on such regions. All sequence data produced with NHGRI funds will be deposited in public databases within 24 hours of quality checking. Other goals

in the plan emphasize new areas of study, including better sequencing technology, human genetic variation, gene function, bioinformatics, the study of model organisms, training, and new priorities for ethical, legal, and social implications (ELSI) activities that will undergird health research for decades to come.

The demand for genomic sequence has also made it an attractive commodity in the private sector. This past year, two private companies announced proposals to sequence the human genome as a for-profit venture. Both plan to use strategies unlikely to produce a complete, highly accurate sequence, though a great deal of data will be generated. Members of the scientific community continue to support the level of quality, completeness, and public accessibility promised by the publicly funded Human Genome Project. Because one of the companies, Celera Genomics, intends ultimately to deposit some of its sequence into a public database, NHGRI is exploring opportunities for collaboration to maximize our respective strengths. Just last month, for example, Celera and an NHGRI-supported scientist at the University of California, Berkeley, signed an agreement to collaborate on sequencing the fruit fly genome.

But even when the first human genome sequence is completed, scientists will continue to sequence many additional genomes from model organisms and disease-causing bacteria and viruses. In fiscal year 1998, NHGRI awarded grants for technology development projects to increase automation, miniaturization, and integration of current approaches to further increase throughput and reduce cost. This year, NHGRI launched a program to integrate the most promising of these new technologies into large-scale genome sequencing labs, where they will be advanced through collaborations between technology developers and users.

The laboratory mouse has become the leading animal model for studying biological processes in mammals. With broad input from the scientific community, NIH has developed a strategic plan for mouse genomics. The NHGRI is leading a bold new trans-NIH initiative to sequence the mouse genome. The first grants will be awarded in September of 1999, with the expectation that sequencing will ramp up rapidly so as to have a high quality draft of the mouse genome sequence by 2003 and the complete sequence by 2005. This sequence will be critical to understanding the function of the human sequence. A number of trans-NIH initiatives are also developing new mouse models for disease, easier access to resources, and better training of specialists.

In the years ahead, information about DNA sequence variation, a natural property of all genomes, will be critical for progress in human genetics research. The most common differences in the human genome, single base-pair differences called "snips" (for single nucleotide polymorphisms or SNPs), occur about every 1,000 DNA bases. Many common illnesses will most likely be influenced by the presence of SNPs in vulnerable parts of the genome, so developing a dense map of SNPs will greatly aid research on diseases such as diabetes, many cancers, and cardiovascular disease. Understanding individual genetic variations may give researchers new clues about why some people are susceptible to a particular illness and others are not. It has already spawned a new area of science called "pharmacogenomics," which aims to maximize the benefits of medicines by identifying individuals for whom the drugs are most likely to be effective and safe. With broad support from 16 NIH institutes and centers, NHGRI has coordinated a large effort to find and map SNPs and deposit them into a public database.

Availability of complete genome sequences is enabling a new approach to biology called functional genomics—understanding how DNA controls the function of complex biological systems in an organism. New methods for studying functional genomics include comparison and analysis of sequence patterns, large-scale analysis of gene products, and systematic approaches to disrupt gene function.

IMPLICATIONS FOR INDIVIDUALS AND SOCIETY

Examination of the ethical, legal, and social implications (ELSI) of genome research has always been an integral and essential component of the Human Genome Project. The NHGRI ELSI program has generated a substantial body of scholarship in the areas of privacy and fair use of genetic information; safe and effective integration of genetic information into clinical settings; ethical issues surrounding genetics research; and professional and public education. The results of this research are being used to guide the conduct of genetics research and the development of related health professional and public policies. The new five-year plan describes new ELSI goals, which include: (1) examining the issues surrounding the completion of the human DNA sequence and the study of human genetic variation; (2) examining issues raised by the integration of genetic technologies and information into health care and public health activities; (3) examining issues raised by the integration of

knowledge about genomics and gene-environment interactions into non-clinical settings; (4) exploring ways in which new genetic knowledge may interact with a variety of philosophical, theological, and ethical perspectives; and (5) exploring how racial, ethnic, and socioeconomic factors affect the use, understanding, and interpretation of genetic information, the utilization of genetic services, and the development of policy.

PROGRESS IN HUMAN GENETICS RESEARCH

Last August, NHGRI's Division of Intramural Research celebrated its fifth year as a cutting-edge research program working to translate the tools of the Human Genome Project into knowledge about human genetic disease and its diagnosis and treatment. In the past year alone, NHGRI intramural scientists have discovered a number of important gene variations associated with neurological disorders, cancer, and other human diseases. Mouse studies have proved invaluable this past year in providing new knowledge about human hereditary disorders, including Huntington disease, lissencephaly, and Hirsch sprung disease.

Prostate Cancer.—In the past, genetic contributions to most common diseases were virtually impossible to sort out. Hereditary predisposition to cancer, for example, usually cannot be explained by a single genetic event, and environmental and possible socio-economic contributions are involved. NHGRI intramural studies of prostate cancer provide a compelling example of how genome project tools are bringing clarity to such scientifically murky health problems. According to the National Cancer Institute, prostate cancer is the most common form of cancer among men. Because prostate cancer clusters in some families, researchers have suspected the disorder has a strong genetic component. That suspicion was borne out two years ago when NHGRI intramural researchers and their coworkers located a region on chromosome 1 that appears to contain a gene variation (HPC1) that predisposes men to prostate cancer. Less than six months ago, the same team of NHGRI researchers found a second site, on the X chromosome (HPCX), that also appears to contribute to prostate cancer. And there will likely be others. In this way, Human Genome Project tools now allow scientists to develop a comprehensive understanding of the causes of cancer, and will ultimately provide a fundamentally new paradigm for sorting out the hereditary, environmental, and socio-economic bases of human illness.

While prostate cancer is common among all U.S. males, it is especially common among African-American men. They are 35 percent more likely than their European counterparts to develop the disease and more than twice as likely to die from it. Researchers based at NHGRI and Howard University are heading a nationwide study that applies the full force of genome technologies to attempt to explain the causes of this apparent disparity. Are men of African descent inherently more susceptible to prostate cancer, and what role do other community-based factors play? The Howard-NHGRI study is being carried out primarily by black scientists and doctors located in seven study centers around the country. They are taking the genome project to the neighborhoods. So far, 28 large African-American families with several affected men have volunteered medical histories and blood samples that will be used to zero in on prostate cancer-related gene alterations on chromosomes 1, X, and others. In the next few years, these studies will bring a much broader understanding of this very common disorder, and ideally suggest new ways to intervene, treat, or even prevent it.

Hereditary Deafness.—Using the recently completed physical map of human chromosome 7, NHGRI intramural scientists and their colleagues have identified an altered gene that results in improper development of the inner ear and is thought to cause as much as 10 percent of hereditary deafness This discovery provides detailed knowledge about a common cause of hereditary deafness and marks the beginning of a better basic understanding of syndromes affecting hearing.

Parkinson Disease.—NHGRI intramural researchers have also identified another genetic piece to the baffling puzzle of Parkinson disease (PD). The finding bolsters their hypothesis that defects in a pathway for disposing of flawed proteins are responsible not only for PD, but for several other late-onset neurodegenerative disorders.

Advanced Technologies for Studying Genetic Disease.—In a new application of the so-called "DNA chip" threads of DNA layered on a postage-stamp sized piece of silicon NHGRI scientists and their colleagues are using large-scale "tissue" chips to illuminate the process of cancer development. They also predict the tissue chip will help researchers learn how to distinguish subgroups of cancer patients and eventually predict which ones will respond to specific therapies. The tissue chip permits processing of massive numbers of biological samples, making it possible for re-

searchers to simultaneously compare DNA, RNA, and proteins, in cancer tissues from hundreds or thousands of patients. In one study, researchers used the device to analyze the activity of several genes believed to play a role in breast cancer. Using the technology, tissue analysis that once took 6–12 months can be accomplished in about a week.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

NHGRI activities are covered within the NIH-wide Annual Performance Plan required under the GPRA. The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the plan's goals.

Mr. Chairman, and Members of the Committee, the seeds of the genetics revolution were planted nearly a half-century ago, when James Watson and Francis Crick unraveled the double helix structure of the DNA molecule, the thread of life. On the threshold of this new millennium, genetics has grown to encompass nearly every aspect of health research and will surely transform not only how we diagnose and treat disease in the future, but also how we stay well.

PREPARED STATEMENT OF DR. JUDITH L. VAITUKAITIS

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget for the National Center for Research Resources (NCRR) for fiscal year 2000, a sum of $469.7 million, an increase of $11 million (or 2.4 percent) above the comparable fiscal year 1999 non-AIDS appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NCRR is $568.1 million, an increase of $13.3 million over the fiscal year 1999 appropriation.

It is a pleasure once again to have the opportunity to discuss the accomplishments and future directions of NCRR. The classic picture of the lone scientist making great discoveries in a small laboratory is a faded image of the past. Research, because of its complexity and use of many sophisticated technologies, has by necessity become multidisciplinary. Unlike the other components of NIH, which focus on particular diseases, organ systems, or areas of research, NCRR supports the infrastructure—such as sophisticated research facilities, advanced instrumentation, and animal models of human disease—that sustains today's multifunctional research enterprise. NCRR's nationwide networks of General Clinical Research Centers, Biomedical Technology Research Centers, Regional Primate Research Centers, and Research Centers in Minority Institutions enable physician investigators and basic scientists to use sophisticated research tools to define the causes of disease, to develop new preventive strategies and to develop and test new drugs to assess novel therapies for diseases that affect majority as well as minority populations in the United States. By developing and supporting research infrastructure and actively promoting initiatives to encourage resource sharing, NCRR facilitates, or catalyzes, biomedical research and stretches the research dollar. Each year more than 20,000 investigators, supported by more than $2.3 billion in primary research support provided by the NIH categorical institutes, use NCRR-supported research resources. Those investigators generate an impressive array of cutting-edge scientific discoveries. For example, animal studies conducted at an NCRR-supported primate research center enabled development and testing of a novel chemical agent for early diagnosis of Parkinson's disease, which affects about 1 million Americans, according to the American Parkinson Disease Foundation. This brain imaging technique also shows promise in ongoing human studies. In the field of structural biology, NCRR-supported biomedical technology centers have offered scientists an unprecedented, in-depth look at the three-dimensional structures of molecules, thus providing new insights into the molecular underpinnings of health and disease.

Scientists using an NCRR-supported synchrotron light source for x-ray crystallography have determined the three-dimensional detailed structure of a potassium ion channel protein. The structure shows how the channel can selectively allow potassium ions to pass through. Investigators at the General Clinical Research Center at the University of Utah determined that a gene responsible for benign familial neonatal convulsions is located on chromosome 20. Affected children typically have seizures during the first 4 days of life, but the seizures spontaneously disappear between 2 and 15 weeks of age. Structural studies of the gene showed that it encodes

a potassium channel protein that has a single amino acid mutation. The resulting dysfunction allows potassium ions to flow into the cell in an inappropriate fashion, thereby altering the excitability of nerve cells and causing epilepsy.

GENETIC MEDICINE

Government-and industry-sponsored research groups in the United States, Europe, and Japan are working to decode the approximately 3 billion building blocks of the human genome. This project, which has a 2003 target date for completion, will profoundly enhance the future prospects of genetic medicine and gene therapy. NCRR, in collaboration with the National Cancer Institute, the National Heart, Lung, and Blood Institute, the National Institute of Diabetes, Digestive and Kidney Diseases, the National Institute for Allergy and Infectious Diseases and the National Institute of Arthritis, Musculoskeletal and Skin Diseases, supports three National Gene Vector Laboratories. Investigators at those sites develop and test gene vectors, which are usually harmless viruses or other substances that transport healthy genes into cells to replace "sick" genes. Although gene vectors must be harmless when used in gene therapy, unwanted side effects can occur and must be carefully evaluated. To facilitate gene vector development, NCRR plans to support toxicology testing of specific classes of gene vectors through the National Gene Vector Laboratories. Individual investigators who use these vectors will thereby be saved the time involved in repeating toxicology studies that already have been done.

Animals—and mice in particular—are invaluable models for studying human diseases, including those caused by genetic abnormalities. Mutant mice have contributed to an understanding of sickle cell anemia, cystic fibrosis, and diseases involving amino acid metabolism, to name a few. But mutant mice are difficult and expensive to develop and maintain by individual investigators. To improve access to these essential resources, NCRR plans to create an integrated network of several Mutant Mouse Regional Resources, abbreviated MMRR. These MMRRs will share a common database and be coordinated and linked electronically. Because of their regional nature, these resources will be responsive to individual investigator needs, and because of their interrelatedness, they will operate efficiently and cost effectively.

It may sound like a utopian dream, but many scientists believe that it one day may be possible to grow replacement organs in tissue culture from cells that have been specifically programmed. Already, skin is routinely grown in large sheets and used to replace skin destroyed by burns or other types of injury. But before complex tissues from the brain, heart, or liver can be reliably reproduced, years of research lie ahead. Studies on pluripotent cells, known as stem cells, can provide important information on how the different organ systems in the body develop and how this development can be controlled and put to good use. Unfortunately, stem cells still are difficult to isolate and culture. To help researchers obtain these critical cells, NCRR plans to support the establishment of a repository and distribution center for nonhuman stem cells and to support research grants to characterize stem cells in nonhuman species. Such stem cell studies may eventually lead to effective treatments for Alzheimer's and Parkinson's disease and to production of replacement heart valves and functional liver tissue.

BIOENGINEERING, COMPUTERS AND ADVANCED INSTRUMENTATION

Ongoing efforts to decode the complete human genome, determine the functions of proteins, and grow specific replacement tissues in culture, lead unavoidably to the Question. How does it all hang together? How do genes produce proteins at exactly the right moments and right amounts? How are different types of cells made and controlled? Scientists in this country and abroad are hard at work to unravel these complex interrelationships. This comprehensive research discipline, known as Integrated Genomics, requires extensive development of new multidisciplinary technologies that can characterize proteins in single cells, and requires expertise in such areas as nanofabrication, bioengineering, laser application, optics, molecular biology, and high-end computing and separation scienceagain underscoring the multidisciplinary nature of health-related research. NCRR intends to support these far-reaching efforts, which will have enormous influence on current biomedical thinking and will likely lead to more efficient treatment of inherited and even acquired disorders.

The detailed functions of individual proteins cannot be understood completely until their three-dimensional structures are known. The brilliant x-rays generated in synchrotrons and used in x-ray crystallography studies allow scientists to determine three-dimensional structures of molecules with unprecedented resolution. But recent successes in sequencing genes from the human, mouse, zebrafish and other genomes have generated many proteins of unknown function which has led to an increasing demand for structural biology studies that threaten to overwhelm the

synchrotron facilities. To help alleviate major access problems at the NCRR-supported synchrotron resources for biomedical research, NCRR plans to provide funding for increased staffing and new detectors that will improve data collection efficiency. NCRR also intends to solicit research project grant applications that emphasize new experimental and computational approaches to solving crystallographic phasing problems. Knowing the three-dimensional structure of proteins will help scientists design targeted drugs and develop more efficient treatment of diseases.

Cell surface molecules known as major histocompatibility complex antigens (MHC) play decisive roles when the body's immune system accepts or rejects foreign biological materials such as transplanted organs or infectious agents such as HIV, the virus that causes AIDS. In the numerous attempts to prepare a vaccine against HIV, scientists often evaluate their experimental vaccines in rhesus monkeys infected with the monkey counterpart of HIV called SIV—simian immunodeficiency virus—which causes AIDS in nonhuman primates. Recently, investigators found a subset of rhesus macaques with an MHC class I molecule that stimulates an immune response to SIV. To be more effectively used in AIDS-related research, rhesus macaques must be screened for this type of MHC class I molecules. To facilitate this screening process, NCRR will establish molecular typing laboratories for analysis of MHC class alleles to identify rhesus monkeys for these traits. This research will help facilitate AIDS vaccine development.

RESEARCH CAPACITY

In all scientific studies it is important to have properly trained investigators, particularly in clinical research. Clinical research is essential for developing new therapies and drugs and finding preventive measures or cures for diseases, but it is difficult to recruit enough well-trained physicians into research careers. NCRR's Clinical Associate Physician (CAP) program—funded through competitive supplements to General Clinical Research Center grants—provides up to five years of early career support to physicians and dentists who plan to become independent clinical investigators. NCRR plans to expand the CAP program to help assure that there are well trained physician investigators to provide a bridge between patient-oriented and basic research.

NCRR also plans to enhance training and career support of well trained investigators in the field of comparative medicine by establishing two types of programs: A two-year fellowship for research veterinarians at the beginning of their careers and a mid-career investigator award for experienced pathobiologists. Pathobiologists are essential for working with other scientists who generate genetically-altered mice and other animal models that frequently have associated developmental defects that can be identified by the pathobiologists.

The activities of the NCRR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. WILLIAM R. HARLAN

Mr. Chairman and Members of the Committee: I am honored to appear before you as the Acting Director of the National Center for Complementary and Alternative Medicine (NCCAM), the newest Center at the National Institutes of Health, to present the fiscal year 2000 President's budget request of $50.2 million, an increase of $1.2 million (2.4 percent) over the comparable fiscal year 1999 appropriation. Funds for NCCAM's efforts in AIDS research are included within the Office of AIDS Research budget request.

The Secretary for Health and Human Services approved the Center on February 1, 1999, as called for in section 301 and title IV of the Public Health Service Act. Considerable work remains to be done as the Center transitions from an office to a Center, and assumes grant review and funding and financial management. The development of a comprehensive research portfolio began with the Office of Alternative Medicine and will be expanded together with an increase in research training and information dissemination.

APPLICATION OF SCIENTIFIC STUDY TO COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

The National Center for Complementary and Alternative Medicine (NCCAM) is dedicated to evaluating complementary and alternative approaches and to providing information about these practices to the public and to health care providers. CAM is defined as medical and health care practices that are not an integral part of conventional (Western) medicine. The public has a growing interest in and increasing use of complementary and alternative medicine. More than 40 percent of the public reported the use of such therapies in 1997 according to a survey by Eisenberg. There are important implications for the health of the public with the widespread use of largely unregulated therapies about which there may be inadequate information. The need for scientifically valid information about therapies is heightened also by the potential for benefit as well as for risk. These benefits and risks can result from use of the preparations and procedures alone or as a complement to conventional therapies. However, evidence for the balance of benefit and risk is not available for most CAM approaches. At a time when medicine and public health are using evidence-based approaches to evaluate conventional therapies, the same standards should be applied to complementary and alternative medicine. There is a growing interest by conventional practitioners and medical scientists in CAM and this is affirmed by a recent series of dedicated articles in the American Medical Association journals. The development of a National Center for Complementary and Alternative Medicine will provide an expansion of research and information dissemination.

The process of evaluation involves research at many steps from basic investigations through small observational studies to large clinical trials designed to provide a definitive assessment of a therapy. The attached schema sketches these approaches and the research mechanisms to support them.

LARGE CLINICAL TRIALS

The Office of Alternative Medicine has initiated several large clinical trials to test CAM approaches that are widely used but lack evidence to support their value. In collaboration with the NIMH, St. John's Wort or hypericum is being tested in a randomized controlled trial as a treatment for depression. This is the most commonly used antidepressant in Germany and one of the 5 most commonly used botanicals in the United States. NCCAM is supporting a trial of glucosamine and chrondroitin sulfate each alone or in combination to determine their effects on osteoarthritis of the knees. Osteoarthritis is increasing dramatically as our population ages and is responsible for impaired quality of life and loss of mobility. The materials being studied, glucosamine and chrondroitin sulfate are derived from animal cartilage and among the most commonly used CAM products, in part because of two books touting their benefits. Another clinical trial is testing acupuncture in the management of osteoarthritis. Yet another large clinical trial is being developed to test whether Ginkgo Biloba can delay the onset of dementia in older persons, for whom it represents a debilitating and expensive condition. This popular herbal has shown modest effects in ameliorating the effects of existing Alzheimer's dementia. The public health implications are very important in terms of quality of life, dependency and health care costs if even a modest delay of onset is possible. NCCAM is also supporting well-designed clinical trials of cancer therapies. Both shark cartilage and a rigid dietary/dietary supplement approach have found considerable support and use in the non-medical and medical communities but the scientific evidence is sparse. Two large trials are being supported by NCCAM and are being conducted by the National Cancer Institute (NCI). The collaboration with the NCI affords an efficient means of utilizing the resources and expertise of the Cancer Therapy and Evaluation Program. Importantly, this collaboration between NCI and NCCAM is being expanded with the development of a Cancer Advisory Panel for Complementary and Alternative Medicine. This panel will evaluate and recommend future studies and diminish the misunderstanding and controversy surrounding CAM therapy in cancer. Will all of these trials confirm the value of the CAM procedures under study? Probably not. But the trials should indicate which therapies have value, which do not, and what are the safety and adherence issues.

CAM RESEARCH CENTERS

The research embodied in these large clinical trials has an extensive background of investigation that extends from study of anecdotal clinical experiences and animal studies to small exploratory studies and on to small-scale trials. A Center program was initiated by the Office of Alternative Medicine 5 years ago with the goal of de-

veloping a core of resources, researchers and collaborators that would investigate promising clinical observations and develop pilot studies aimed at building a base for larger and more definitive clinical trials. The Centers program is being expanded under the National Center for Complementary and Alternative Medicine to include new areas of interest and to increase support for individual research projects that will move the research toward evidence-based statements of CAM practice. The Centers have brought together researchers from the CAM community and experienced scientists with strong methodological skills. The CAM Research Centers focus on: cancer, cardiovascular disease, HIV/AIDS, pediatrics, musculoskeletal disorders (with emphases on rheumatoid diseases and osteoarthorits), neurological disorders and stroke, substance abuse, and problems associated with aging. The robust response to the recent requests for Center applications has provided an opportunity to select the most meritorious from among a wealth of very good proposals. These Centers also afford outstanding opportunities for research training.

GRANT SUPPORTED RESEARCH

The National Center for Complementary and Alternative Medicine will review and fund investigator-initiated research grants using the usual NIH peer-review system. As an office these grants were reviewed and funded through Institutes and Centers although the initiation of requests were developed jointly by the Office and a sponsoring Institute or Center (IC). These investigator-initiated studies include basic investigations of mechanisms, field investigations of reported therapeutic successes, and exploratory studies and small trials. The NCCAM will continue to benefit from the interest and active participation of staff from other IC's at NIH and from collaboration with other agencies. The important scientific assistance provided by other IC's will continue by having a designated liaison scientist for each Institute and Center. These scientific liaisons will attend scheduled meetings that will also include liaisons from other health agencies. These interagency coordinating meetings began in 1997 and have fostered inter-agency agreements with AHCPR and CDC. The evidence-based practice centers program of AHCPR will be tasked to develop evidence-based reviews of selected CAM practices as designated by NCCAM. CDC has an agreement to conduct field investigations of practice experiences with CAM and to report on their findings. In both instances, the unique resources of these agencies are being used to complement studies supported by NIH and this information provides direction for future studies.

RESEARCH TRAINING

Research training has a critical role in advancing research in CAM. Both the conventional and CAM communities have expressed an interest in conducting CAM research. Both groups need training in design and conduct of clinical research and in addressing the unique issues presented in studying CAM modalities. The Centers program has facilitated training by bringing together a critical mass of CAM investigators and projects that became the focus of research training. The current recompetition of the CAM Research Centers contains 10 percent of direct costs for allocation to training and career development at each Center. Training and fellowship awards have been made to trainees working in these Centers and as supplements to other grants. NCCAM is participating in the mentored clinical research awards that provide support for those who have finished clinical training and want support to transition to a research career. The intramural research training program began in fiscal year 1998 and currently four fellows are being supported. These fellows take the core course on clinical research and are working in intramural laboratories on CAM topics. Their projects merge conventional research methodologies with issues in CAM.

INFORMATION DISSEMINATION

Providing current and reliable information to the public and to healthcare providers is important to assist in decisions about the use of CAM approaches and about research opportunities. NCCAM has several publicly available information sources. A Public Clearinghouse provides information for those who call a toll-free number (1–888–644–6226). Operators can respond to inquires in English or Spanish. They provide information that has been reviewed for its accuracy. About 1500 inquires are handled each month and the number continues to grow. Information is available on the web site at http://altmed.od.nih.gov and consists of current activities in NCCAM and information on CAM approaches. An on-line bibliographic database dedicated to CAM is accessible at this address. There are over 140,000 citations available and we expect to add about 25,000 additional citations this year. This is a useful resource for health providers and researchers as well as the public.

There have been about 54,375 searches conducted thus far and all but 1500 have been from outside of NIH. NCCAM has been accepted into the Combined Health Information Data (CHID) system that aggregates health information for the public on numerous topical areas related to health and disease. Information on CAM therapies is available along with information on conventional therapies. Informational materials on CAM cancer therapies are being revised cooperatively with the National Cancer Institute (NCI) and will be available at the web sites of both NCI and NCCAM.

GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The activities of the NCCAM are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congressional feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. GERALD KEUSCH

Mr. Chairman and members of the Committee. I am pleased to present the President's non-AIDS budget request for the Fogarty International Center (FIC) for fiscal year 2000, a sum of $23.5 million, which reflects an increase of $553 thousand (2.4 percent) over the comparable fiscal year 1999 appropriation. Including the estimated allocation for AIDS, total support requested for FIC is $36.2 million, an increase of $.8 million over the fiscal year 1999 appropriation. Funds for the FIC efforts in AIDS research are included within the Office of AIDS Research budget request.

The programs of the FIC, developed in consultation with the Committee, reflect the strength of our commitment to protect the health of Americans and reverse the deepening disparities in global health status. As the late physician-philosopher Lewis Thomas noted in an essay on global health: "We have an obligation to assure something more like fairness and equity in human health. The idea that all men and women are brothers and sisters is not a transient cultural notion. . . . It is a biological imperative."

This is my first appearance before you as FIC Director and NIH Associate Director for International Research. Before describing our progress over the past year and proposed new directions, I would like to note my gratitude for the support NIH has provided to me and my colleagues for international work. My own studies on global urgencies such as malnutrition and diarrheal disease have demonstrated to me the profound repercussions of a nation's health on societal and economic well-being, and the importance of bringing together diverse scientific disciplines to confront major health concerns. I hope to foster new partnerships among institutions involved in global health, including development agencies and industry, to ensure that our research efforts translate into public health tools and interventions for the benefit of all people.

I also will emphasize the importance of applying molecular and cell biology to clinical studies and epidemiological field work. The promise of "molecular medicine"—our capacity to identify, amplify, clone and utilize genes for clinical benefit—carries great implications for the development of vaccines, diagnostics and drugs for diseases which threaten populations at home and abroad. I look forward to working with the Committee to set aggressive but achievable target objectives for FIC as part of an overall NIH research campaign to reduce global health disparities and to create a new "molecular global public health" agenda.

Over the past year, FIC celebrated its thirtieth year as the NIH component dedicated to promoting research and training in global health. These three decades have witnessed significant breakthroughs fostered by international collaborative research, such as the discovery of genes responsible for cystic fibrosis and Huntington's disease; but equally important, a realization that the health and well-being of our population cannot be separated from the welfare of populations elsewhere in the world. One million people travel between the developing world and the U.S. or other industrialized countries every week. Despite all the advantages of an interconnected world, trade and travel are inevitably associated with the transfer of health risks: infectious diseases, contaminated foodstuffs, toxic substances, antibiotic resistant microbes, to name a few.

Tuberculosis, HIV/AIDS, influenza, and dengue fever recognize no geographic boundaries nor political allegiances, and what happens on the far reaches of the globe can have troubling repercussions in U.S. hospitals. For example, unregulated, widespread use and misuse of anti-microbial drugs in the developed and developing countries has led to the emergence and global spread of drug-resistant pathogens such as Streptococcus pneumoniae, which is a common cause of life-threatening bacterial pneumonia and is responsible for most episodes of otitis media, the most common cause of pediatric physician visits in the United States. FIC research and training activities range from partnering with the world's foremost scientists to better understand and ultimately prevent diseases such as cancer, malaria, or HIV; to developing methods for rapid identification of emerging, reemerging and pandemic infections; to developing and testing drugs and vaccines. FIC also supports studies of unique environmental exposures such as those in Chernobyl, where researchers are improving our understanding of radiation and childhood cancer. American leadership in international biomedical research is needed to protect U.S. citizens from disease, strengthen our economy, advance U.S. interests abroad and fulfill our humanitarian aspirations. Our battle to prevent and cure HIV/AIDS is a dramatic example of the convergence of these purposes. AIDS has exacted a profound humanitarian toll; reversed gains in child survival in many African nations; and reduced the economic stability of emerging markets due to its mortality toll on the productive workforce. This situation has an adverse effect on international trade and, potentially, political stability. Major leaps in our understanding of the biology, epidemiology, clinical manifestations and progression of HIV infection have come from international research. An exciting example involves FIC AIDS International Training and Research Program-sponsored longitudinal studies of volunteers in Kenya who have not become infected with HIV despite multiple exposures. This research, carried out in cooperation with the Universities of Washington and Nairobi and the National Institute of Allergy and Infectious Diseases (NIAID), helps us understand how some people resist HIV infection and may pave the way for the development of new drugs to inhibit the virus from penetrating and multiplying within target cells.

PROGRAM PROGRESS AND ACCOMPLISHMENTS

With increases provided by Congress this fiscal year, FIC is supporting U.S. institutions in launching new or expanded international research and training efforts in HIV/AIDS, as well as environmental health, maternal and child health, and cancer etiology and risk. We are expanding our international program in medical informatics to enable scientists in Africa and Latin America to access the scientific resources of NIH through the Internet and to assist U.S. scientists to develop global scientific partnerships. Since the FIC last presented to this Committee, FIC-sponsored investigations conducted by scientists at Case Western Reserve University and the Ugandan Ministry of Health have identified drug regimens that prevent active tuberculosis among HIV-infected adults, findings that are applicable to the Global Programme on Tuberculosis of the World Health Organization. FIC also is examining the role of multivitamin supplements as a prophylactic and therapeutic measure for individuals infected with HIV through joint studies conducted by Muhimbili University College of the Health Sciences in Dar-es-Salaam and Harvard University. Expanded prevention research may lead to low-cost, health-promoting therapies for those who cannot afford expensive anti-retroviral drugs. Other FIC-supported research involves international monitoring of the genetic variability of the different strains of HIV, providing the epidemiological data required for the production of candidate vaccines.

Chemicals, radiation, microbial contaminants and other environmental agents cause a host of acute and chronic illnesses as well as birth defects. These effects often are documented first among highly exposed populations in other countries. Additional support to the FIC International Training and Research Program in Environmental and Occupational Health is promoting long-term, cross-cultural studies to examine the effects of environmental agents on health. In the Czech Republic, for example, investigators are assessing the long-term effects of pesticides and lead exposures on the nervous system. In Colombia, a study of exposure to benzene and other aromatic hydrocarbons may improve our understanding of their relation to neurobehavioral disorders. These and other projects may assist nations and international organizations in developing evidence-based safety standards for the environment and workplace.

International studies also provide opportunities to elucidate the etiology of diseases with diverse and sometimes interactive environmental and genetic causes, such as breast cancer. The incidence of breast cancer is increasing worldwide with

the highest rates occurring in industrialized countries. As developing nations make the transition to industrialized economies, breast cancer incidence rates begin to rise dramatically. This suggests that changes in the prevalence of environmental or behavioral risk factors may be important contributors to the disease. Supported by a Fogarty International Research Collaboration Award, scientists at the University of Washington who identified the breast cancer gene (BRCA1) earlier this decade are now assessing the role of environmental and genetic factors in breast cancer among patients in Hungary and Chile. The study examines such potential influences as hormone therapy, diet and smoking. The ultimate aim is to identify risk factors which may be modified to reduce risk in our own population as well as the populations under study.

One of the more menacing outcomes of environmental change and demographic pressure, with irreversible and unpredictable consequences, is the loss of biological diversity. A key implication is the loss of potential new medicines derived from biological resources such as plants, invertebrates and marine organisms. The FIC International Cooperative Biodiversity Groups, an international consortium of academic institutions, foundations and pharmaceutical companies, has identified over two dozen potential therapeutics from natural products, including a compound that shows strong activity against tuberculosis. The biodiversity initiative is co-sponsored by the National Science Foundation and several of our sister institutes at NIH. Thanks to your support, this, and more, is already happening. Now, let us look forward.

NEW INITIATIVES FOR FISCAL YEAR 2000

In fiscal year 2000, FIC proposes to launch several interdisciplinary initiatives in concert with other agencies and NIH institutes. As an outgrowth of the biodiversity program and in cooperation with NSF and NIAID, FIC is conceiving a program to assess habitat-level changes in biodiversity which may have consequences for disease agents, domestic and wild animal reservoirs, and insect vectors. Lyme disease, cholera and hantavirus are notable examples. There also are important and novel scientific leads to be pursued with other diseases. Studies from China, for example, suggest that selenium deficiency in soil alters the viral genotype and increases the virulence of the coxsackie virus, resulting in a life-threatening heart condition known as Keshan's disease. This is the first report of a nutritional deficiency altering viral genes and may have implications for our understanding of microbial ecology and virulence.

Because research and research ethics go hand-in-hand, FIC proposes to develop novel training programs designed to increase the number of investigators in developing nations with expertise in applied research ethics. Through fellowships and international workshops, in consultation with WHO, UNAIDS and others, FIC's bioethics training program will focus on the responsibilities of institutional review boards, such as risk-benefit analysis, levels of care for control groups, informed consent, and emerging issues such as collection and use of DNA samples. Our objectives are twofold: scientists from developing nations will gain deeper insights into U.S. procedures for ethics review, and NIH participants will improve their understanding of local considerations in interpreting and implementing ethical precepts in internationally-based research.

An initiative to be planned in cooperation with the World Bank will examine the economic implications of health investments. Just as wealth may lead to improved health, the converse also may be true: several lines of evidence suggest that health may be a precondition for economic enrichment of a society at the population level and for its lowest income groups at the household level. For example, economists have identified a correlation between reductions in malaria prevalence and increases in economic productivity, as measured by various macroeconomic indices. Support will be provided to interdisciplinary teams of economists and health scientists from the U.S. and developing nations. The practical intent of this initiative will be to provide empirical data to assist development banks, bilateral and multilateral donors and finance ministries to determine priorities for health research and development investments.

CONCLUDING REMARKS

Mr. Chairman, the premise of our programs is that research, and building research capabilities, are prerequisites to reversing our internal and global disparities in health, just as good health is instrumental to economic development and productivity. Research is required to guide strategic policies against global health threats. Without it our actions can be inefficient, or even worse, wholly ineffective. The example par excellance in our century is the eradication of smallpox. The original

global prevention strategy was mass vaccination, yet transmission persisted. Scientists conducted rigorous investigations on patterns of illness and developed a targeted, cost-effective strategy of cluster vaccination around active cases. Through international cooperation, the disease was eliminated within ten years, and at a fraction of the cost of mass vaccination. With the continuing support of Congress, we will work with our domestic and international partners towards the ultimate aim of replicating this success against global threats that exact such a huge humanitarian toll and social cost. The FIC particularly looks forward to working closely with the World Health Organization under its new Director-General, Dr. Gro Harlem Brundtland, on both infectious and chronic disease priorities.

The activities of the FIC are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DONALD LINDBERG, M.D.

I am pleased to present the President's budget request for the National Library of Medicine (NLM) for fiscal year 2000. The fiscal year 2000 budget provides that NLM receive $181.4 million, an increase of $4.2 million (2.4 percent) over the comparable 1999 figure. Including the estimated allocation for AIDS, total support proposed for the NLM is $185.7 million, an increase of $4.3 million over the 1999 appropriation. Funds for NLM's AIDS efforts are included within the NIH Office of AIDS Research request.

HEALTH INFORMATION FOR CONSUMERS

Today's American is a more savvy "consumer" of health care than the patient of just a few decades ago. Society is awash in health information, and knowledgeable consumers can quickly find advice. The news media carry frequent stories about health and medicine; it seems as if the New England Journal of Medicine and the Journal of the American Medical Association are cited as sources for stories as often as the Associated Press. Not all health information available to the public is so well grounded. Some of the information "out there" is of suspect quality, and not everyone has access to the Internet (where much of the data resides). The National Library of Medicine sees in this situation a need and has launched an initiative to address both these problems.

When the NLM discovered that one third of the 140 million MEDLINE searches being done each year are being done by the public, for their personal health and the health of their families, the Library immediately began planning a new program to reach out directly to consumers. MEDLINE*plus* was created as part of this effort and introduced on October 22, 1998. It provides Web users with access to reviewed, authoritative health information—from the NLM, the National Institutes of Health, other government agencies, and from selected non-government organizations. The new service provides access to extensive information to 45 diseases and conditions (cancer, diabetes, etc.) and also has links to self-help groups, NIH consumer health information, clearinghouses, dictionaries, lists of hospitals and physicians, health information in Spanish, and clinical trials. The number of health topics is being expanded as rapidly as possible; NLM projects the 45 topics to be increased to several hundred in the coming months. One unique feature of MEDLINE*plus* is a series of preformulated MEDLINE searches on various aspects of diseases that return up-to-date material useful to the general public. MEDLINE*plus* is the centerpiece of a new pilot project that is helping to address the second problem identified above: the lack of Internet access by many of the public. The plan devised by the NLM is to train local public librarians to use the Internet to find health information responsive to their patrons' needs. In the pilot project, begun at the same time MEDLINE*plus* was introduced, NLM is working with 37 representative public library systems (more than 200 libraries in all).

A new project with enormous potential for the public is the effort to create an easy-to-use database containing information about clinical trials, whether federally or privately funded, for experimental treatments for serious diseases and conditions. The database is being developed in stages, with NIH-sponsored trials as the first

module. It will allow nonscientific users to understand the purpose of a clinical trial, the eligibility criteria for participating, where it is being conducted, and how to get in touch with those conducting it. The Library plans to create a central search engine that will provide a uniform interface to all clinical trials and thus simplify the task of finding information. One route of access to the clinical trials database would be via MEDLINE*plus*.

SPECIAL TARGET AUDIENCES

Recognizing that poor neighborhoods suffer disproportionately from toxic waste sites and other environmental hazards, the NLM has a program to train health professionals, community leaders, and others in these areas to use TOXNET, NLM's set of databases with information about toxicology, environmental health, and hazardous wastes. Working through Historically Black Colleges and Universities (HCBUs), the Library provides state-of-the-art equipment, software, and free online access to computerized information sources for more than 60 institutions. As a result, online searching has been integrated into curricula, and training classes are held at the HBCUs for researchers, instructors, students, and health professionals in neighboring communities. The success of this program is encouraging us to expand the network to community centers, churches, state health organizations, and other groups that communicate directly with concerned citizens.

Another outreach initiative targeting a special audience is the "Partners in Information" program in which NLM has made awards to public health officials to help them hook up to the Internet and make it easier to access health information. Public health officials at the state and local level, as a group, have inadequate access to information services and technology. The new program allows them to get training and have access to information and advanced telecommunications so that they will be better equipped to deal with public health challenges. The program is a joint activity of the NLM and several federal and nonfederal groups, including the Centers for Disease Control and Prevention. The awards are scattered around the U.S. in rural and underserved areas and involve information services for public health officials who are addressing a variety of community health problems and special populations.

NLM's outreach activities have an international component that is also receiving special attention. The Library has always emphasized collecting and organizing the medical publications of other countries; this is reflected in the international character and usage patterns of MEDLINE and the other databases. A Long Range Planning Panel on International Programs was set up by the NLM Board of Regents and, in its final report, issued in 1998, the Panel recommended that the Library expand its involvement with other governments and with non-U.S. health science institutions. One international program, undertaken at the request of the NIH Director, is to participate in the Multilateral Initiative on Malaria by enhancing the communications and networking capabilities of African malarial researchers.

MEDICAL INFORMATICS

The NLM is supporting cutting-edge research that seeks to learn how the capabilities of the Next Generation Internet (NGI) can be used to improve health care, health education, and medical research. One aspect of this support is to fund pertinent studies by the National Academy of Sciences (most recently "Enhancing the Internet for Medical Applications: Technical Requirements and Implementation Strategies"). The NLM itself depends to a great extent on the Internet to deliver health information services, and it thus has a vested interest in promoting the health of the network. The NGI initiative is a partnership among industry, academia, and government agencies that seeks to provide affordable, secure information delivery at rates thousands of times faster than today. If we can transmit massive amounts of data quickly, and with accuracy and security, will this lower health costs, increase the quality of care, and safeguard patient privacy?

The NLM is supporting a number of investigations aimed at finding answers to these questions. Some are "tele-" projects: telemedicine, telepresence, teleconferencing, tele-immersion, telemammography, teleradiology, and teletrauma. Others are aimed at speeding life-saving treatment to heart attack victims. Working with the National Heart, Lung, and Blood Institute, the Library is trying to find out if the techniques of medical informatics can help ensure that known clot-dissolving agents are applied immediately after a heart attack. If successful, NLM's program would be a dramatic example of how timely information can potentially save many thousands of lives.

Several of NLM's technology-based programs have an educational focus. One new one is "Profiles in Science," a web site that allows the user to look behind the scenes

of scientific discoveries at the unpublished writings, letters, photographs, and lab notes of great scientists and great scientific discoveries. The first two collections are for Oswald Theodore Avery and Nobelist Joshua Lederberg. The new web site, which brings together the best in archival practices with state-of-the-art technology, will be continually enriched with the papers of great scientists of this century. Another program with important implications for education and training is the Visible Human Project, which continues to command great interest in the scientific community and public media. The two datasets, which contain detailed, submillimeter, anatomical images of a male and female, are being used (without charge) by more than 1,000 licensees in 30 countries. Some of the educational uses to which they are being put are "surgical simulators" that let doctors rehearse delicate medical procedures on computer and "recyclable cadavers" to help medical students learn about anatomy via computer. The NLM is cooperating with three other NIH Institutes to fund jointly the development of an interactive, Internet-accessible atlas of head and neck anatomy based on the Visible Human Project data sets.

GENETICS OF MEDICINE

Eleven years ago the Congress, anticipating the virtual explosion of genomic information and the growing importance of molecular biology, created the National Center for Biotechnology Information (NCBI) as part of the NLM. By creating and maintaining immense databanks to receive and organize this information, and the sophisticated tools that allow it to be used in making further discoveries, the NCBI is making a major contribution to the Human Genome Project. Scientists in universities, research institutions, government agencies, and commercial organizations worldwide have come to depend on the NCBI as the authoritative source of molecular data and data-manipulation tools, and they submit the results of their work to the Center's highly evolved information resources so that the data will be available for use by others. One result of the accelerating pace of research is that the GenBank database of DNA sequence information is growing to gargantuan proportions. It now contains some 3 million sequences with a total of 2 billion base pairs, and the NCBI web site, where GenBank is made freely available, receives some 4.5 million "hits" per day from 100,000 scientists and others around the world. Not only do they use GenBank, but they avail themselves of sophisticated computational tools, such as the BLAST suite of programs for conducting comparative sequence analysis. Another such tool is Entrez, which links information, including the literature, sequences, structures, and taxonomy.

NCBI scientists are working closely with colleagues in other Institutes to create new capabilities in our fight against disease. One example we mentioned last year is the National Cancer Institute's Cancer Genome Anatomy Project (CGAP). This research is an effort to characterize normal, pre-cancerous, and malignant cells at the molecular level, and may lead to new therapies and diagnostic tools. NCBI scientists, working on the communication aspects of the project, are making it available on the web. Another collaborative project is with the National Institute of Allergy and Infectious Diseases to develop a web resource of genetic data related to the parasite responsible for most cases of malaria. NCBI scientists have also collaborated with colleagues in laboratories around the world to produce a new "gene map" that pinpoints the chromosomal locations of almost half of all genes. This milestone in the Human Genome Project, available to all on the World Wide Web, will greatly expedite the discovery of human disease genes and, by extension, contribute to advances in detection and treatment of common illnesses.

THE MEDICAL LITERATURE: BEDROCK OF NLM SERVICES

The advanced information products and services of the National Library of Medicine are built on the foundation stone of its unparalleled collections. They are broad (encompassing all the health sciences) and deep (from the 11th century to the present). The Library subscribes to more than 22,000 serial publications and serves as a "court of last resort" for published biomedical information in all forms. Extensive use is made of this collection: NLM responded to almost 700,000 requests for copies of articles and books in 1998, by e-mail, fax, post, and on-site patrons. The Library was able to handle this record workload with the help of a new document delivery system that uses scanning and electronic communications technology to process requests much faster, with less effort and paperwork, and with a higher quality copy being delivered to the requester. Clinical emergencies have special priority; doctors a thousand miles away have been astounded to receive a copy of an article from the NLM within a half hour. Much of the Library's progress, including this new system, has been achieved under the "System Reinvention" banner. Other examples are the access programs that make MEDLINE freely available on the

World Wide Web and a new "integrated library system" that greatly improves internal processes and provides the same easy web access to book and audiovisual materials that MEDLINE users presently enjoy for the journal literature.

One of the most important factors in the widespread acceptance and use of NLM's information services is the role played by the National Network of Libraries of Medicine. The NN/LM, with its 4500 members, is organized through eight regions, each with a Regional Medical Library designated and supported by the NLM. Those institutions, together with 140 large academic health science libraries and the many hospital and other libraries in the network, provide crucial information services to scientists, health professionals, and, increasingly, the public. The public library initiative, described above, would not be possible without the help of network libraries.

The activities of the NLM are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress's feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PREPARED STATEMENT OF DR. NEAL NATHANSON

I am pleased to present the President's budget request for the AIDS research programs of the National Institutes of Health for fiscal year 2000, a sum of $1,833.8 million, an increase of 2.0 percent above the comparable fiscal year 1999 appropriation. The activities of the OAR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 2000 performance goals and measures for NIH are detailed in this performance plan and linked to both the budget and the HHS GPRA Strategic Plan that was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

The mandate of the Office of AIDS Research (OAR) is to set the scientific agenda by planning, coordinating, and evaluating the vast and diverse NIH AIDS research program and by developing the AIDS research budget, based on the most compelling scientific priorities that will lead to better treatment and prevention of HIV infection and AIDS. We establish these priorities through a collaborative process involving all of the NIH institutes as well as non-government experts from academia and industry, with the full participation of the AIDS-affected community.

Mr. Chairman, these are my first Congressional hearings. I came to NIH last summer from semi-retirement after a long academic career in the field of viral pathogenesis and epidemiology. My early career was devoted to the control of the polio epidemic. My experiences during that epidemic shaped my decision when Dr. Varmus asked me to come to Washington to head the OAR. I accepted the job based largely on three beliefs: first, that AIDS is the most devastating and critical public health epidemic to threaten the world in our lifetime; second, that, as we demonstrated with polio, it is possible to bring epidemics under control with an intense and well-managed research effort; and third, that the scientific breakthroughs we find for AIDS will also provide discoveries benefiting a whole host of life-threatening illnesses that we know and even some that we don't yet know—those potential epidemics we will confront in the future. My testimony before you today is built around those three themes.

THE UNRELENTING PANDEMIC

By any criterion, AIDS must be considered the great plague of the 20th century. The magnitude of the pandemic is truly profound. The disease already has killed nearly 14 million people worldwide since its appearance in the late 1970s. Presently more than 30 million people are living with HIV/AIDS, most of whom will die in the next ten years. AIDS has significantly lowered the life expectancy in many nations of Africa, the global epicenter of AIDS. The first chart graphically shows the steep increase of new infections in Sub-Saharan Africa, but dangerous and burgeoning disease rates also threaten the vast populations of India, Southeast Asia,

and China. Rapid increases are occurring in Eastern Europe and Central Asia, and HIV remains a serious threat in Latin America and the Caribbean.

In reality, the pandemic consists of many distinct sub-epidemics. In the U.S., for example, the overall death rate due to AIDS has declined (chart 2). But it is critical to understand that the true picture of the epidemic is not reflected by death rates, because the rate of new HIV infections has not changed. That means that although we are delaying death, at least for a time, we have not slowed the epidemic. New HIV infections and AIDS-related deaths continue to increase alarmingly in many subpopulationsamong women, racial and ethnic minorities, heterosexuals, adolescents, drug users, and people over 50 years of age (chart 3). AIDS continues to affect those most disenfranchised in our society—the poor, the homeless, and those with addictive or mental disorders. AIDS remains one of the leading causes of death among all Americans aged 18 to 45, and it is the number one cause of death among African American men in that age group. While the epidemic has stabilized among white gay men overall, it is increasing among younger homosexuals.

A TRANSMISSIBLE DISEASE

The transmissible nature of HIV—between individuals and across borders and populations—makes it radically different from non-transmissible diseases such as heart disease and cancer. There is the potential for unlimited spread, but there is also the possibility for control of the pandemic—in a way that can never be possible for noninfectious diseases. The impact of an intervention that reduces the probability of transmission, breaking the link in the epidemic chain, extends far beyond the treated or protected individual. Chart 4 shows the results of our efforts against two other infectious diseases, tuberculosis and polio, which were brought under control through effective therapeutic and preventive interventions. It illustrates why I took this job and why I believe that our research efforts can, and must, bring about a similar result for AIDS.

But we remain discouragingly far from that goal. The changing demographics of the epidemic demand careful consideration as we plan our research agenda, because different prevention and intervention strategies must be applied to each subepidemic, here and around the world. Through the annual AIDS research plan and this budget, OAR is focusing the NIH AIDS research enterprise on what we have named "intervention research," targeting both short and longterm opportunities to prevent transmission and to treat infection and disease.

PRIORITY FOR INTERVENTION: BETTER THERAPIES

Ground breaking research in basic biology, spearheaded by NIH and fostered by my predecessor, Bill Paul, has revolutionized drug design that is benefiting the fight not only against AIDS, but against other diseases. This basic research was the foundation for the development of a new class of drugs, known as protease inhibitors, that are extending the length and quality of life for many HIV-infected individuals here in the U.S. (chart 5). But the list of serious problems associated with these new therapies is long: Even with therapy, the virus has not been completely eliminated from the body and may still be transmissible. We do not know how long the benefit of therapy will last or whether immune function of treated individuals can be restored. There are many for whom the new drug regimens have not been effective or for whom the side- effects are not tolerable. Serious complications of therapy are being identified, including metabolic disorders and deforming lipid deposits. Many patients are unable to adhere to the complicated drug schedules. Drug resistant viral mutants are beginning to emerge, representing a new and dangerous threat to public health. We have an urgent challenge to develop simpler, less toxic, cheaper drug regimens; new generations of antiviral drugs directed against different viral components; therapies to reconstitute immune function in treated patients; and more effective methods to enhance access and adherence to complex therapeutic regimens.

PRIORITY FOR INTERVENTION: WOMEN AND MINORITIES

Heterosexual transmission, the primary route of HIV infection worldwide, accounts for an increasing proportion of new infections among women and racial/ethnic minorities in the U.S., and we are directing resources toward new interventions that will have the greatest impact on these groups. For example, we are supporting research to understand the pathogenesis of HIV disease in women and to develop effective and acceptable female-controlled methods to block HIV transmission, such as microbicides.

On October 27, 1998 the Administration and the Congressional Black Caucus announced a major initiative to address the disproportionate impact of HIV/AIDS in

minority populations. In addition to the $359.3 million investment in fiscal year 1999 (chart 6) already targeted to AIDS research in minority populations, OAR, in collaboration with the Office of Research on Minority Health and the Office of Research on Women's Health, allocated an additional $7 million for the new initiative. These funds will support projects to: increase the number of minority investigators conducting behavioral and clinical research; target the links between substance abuse, sexual behaviors and HIV infection; and increase outreach education programs for minority physicians and at-risk populations.

NIH has devoted resources to improve research infrastructure and minority training opportunities, and we will continue to assure the participation of minorities in clinical trials and in natural history, epidemiology, and prevention studies. We are focusing on interventions that address co-occurrence of other STDs, hepatitis, drug abuse, and mental illness, and those that consider the role of culture, family, and other social factors in minority communities.

PRIORITY FOR INTERVENTION: THE QUEST FOR AN AIDS VACCINE

To control the pandemic for all individuals, communities, and nations at risk, a safe and effective vaccine is the critical missing element in our armamentarium. Vaccine research remains one of the highest priorities, and my personal consuming goal. With this budget request, NIH will have increased funding dedicated to the discovery of an AIDS vaccine by more than 100 percent over the past 5 years (chart 7). The AIDS Vaccine Research Committee, chaired by Dr. David Baltimore, and on which I serve, is pursuing new avenues for vaccine investigation. Construction of the NIH Vaccine Research Center is underway.

Existing vaccines were developed against acute viral illnesses. None of those were as difficult to formulate as an AIDS vaccine, in part because of the persistent and insidious nature of HIV. We are beginning to unravel a wide variety of questions about the structure of the virus, the way it stimulates the formation of antibodies, the protective role of different components of the immune response, and the mechanism of viral escape from immune surveillance. It will probably be important to utilize primate models to screen a multitude of candidate immunogens and then to test the most promising products in human clinical trials.

PRIORITY FOR INTERVENTION: INTERNATIONAL RESEARCH

Because HIV has spread readily around the globe, without respect to political boundaries, it can only be controlled through a global program of interventions. More than 90 percent of new infections occur in developing countries, where therapeutic interventions are unaffordable and undeliverable. NIH must pursue interventions that can be implemented in these resource- and infrastructure-deprived nations. Our vaccine research efforts underscore the crucial role of NIH in addressing prevention and treatment needs worldwide. In addition, a recent clinical trial demonstrated that a modified less expensive AZT protocol, could reduce mother-to-child transmission by 50 percent. NIH has established research and training programs in many developing nations. To further these efforts, OAR has established an International AIDS Research Collaborating Committee to bring together all of the Departments of the U.S. government conducting AIDS research and our international partners, including the UN Joint Programme on AIDS and the World Bank.

BENEFITS TO OTHER DISEASE RESEARCH

Because of the unique nature of HIV—the way the virus enters a cell, causes infection, affects every organ system, and unleashes a myriad of opportunistic infections and cancers—and the pace at which the knowledge base has been expanded, AIDS research is also unraveling the mysteries surrounding many other infectious, malignant, neurologic, autoimmune and metabolic diseases. AIDS research has provided an entirely new paradigm for drug design and development to treat viral infections. The drug known as 3TC, developed to treat AIDS, has been shown to be the most effective therapy for chronic hepatitis B infection. Drugs developed to prevent and treat AIDS-associated opportunistic infections also provide benefit to patients undergoing cancer chemotherapy or receiving anti-transplant rejection therapy. AIDS research has provided vast information about human immunology and immune reconstitution, and is providing new understanding of the relationship between viruses, the immune system, and cancer. The investment in AIDS behavioral and social sciences research has provided effective strategies for intervening in other diseases modified by individual behavior. AIDS has revolutionized the way we conduct research, empowering patients, particularly women and minorities, to participate in clinical trials, in the design and implementation of research protocols, and in setting priorities for this research.

The budget authorities provided to OAR, allowing us to direct resources to the most important scientific priorities, are even more critical today as scientific opportunities change and funding levels fluctuate. The Nation has made a wise investment of resources in the NIH AIDS research program, and we are deeply grateful to the Committee for your steadfast support. I believe that this investment will ultimately yield a high return for the nation and the world.

PROFESSIONAL JUDGMENT BUDGET

Senator SPECTER. Well, thank you very much, Dr. Varmus.

I appreciated the brief meeting you and I had the week before last, and I had asked for NIH proposals on what could be accomplished with additional, substantial additional funding. We will make all of that a part of the record.

I am pleased to see that there is a public disclosure of the desired figure of $19.3 billion. Am I incorrect about that?

Dr. VARMUS. I am not certain. That number, of course, is the number that you requested as a professional judgment budget. The numbers we actually submitted to the Office of Management and Budget and the Department earlier in the process were considerably lower than that.

Senator SPECTER. Well, we like your professional judgment, Dr. Varmus.

Dr. VARMUS. Thank you.

Senator SPECTER. We understand the constraints of the Office of Management and Budget. We understand you are a team player.

Is this Dr. Varmus' yellow light?

Ms. TAYLOR. Yes.

Senator SPECTER. It is not my yellow light. [Laughter.]

Dr. VARMUS. Always pleased to be under time and under budget.

Senator SPECTER. Well, those are commendable traits, Dr. Varmus.

But the $19.3 billion figure is what you think you need in order to carry out the research and handle the applications and the grant requests which are before the various Institutes, correct?

Dr. VARMUS. That number represents what we could do under optimal fiscal conditions if we were to exploit in a reasonable way all of the opportunities that are before us. We do think we can operate effectively under the President's budget and under many intermediate phases of funding.

Senator SPECTER. Well, we understand your effective operation and you are a team player. But we appreciate the other figure so we have a guidepost.

The figure that I asked you privately I think ought to be put on the record here. The $2 billion which has been added is a figure which you can assimilate and can use efficiently, correct?

Dr. VARMUS. Absolutely. We have documented that very carefully for 1999 with the tables that I have provided to you and many Institutes have also provided to you.

CERVICAL CANCER MORTALITY

Senator SPECTER. Let me ask for a very brief response from Dr. Klausner on the headlines today about cervical cancer mortality could be cut by half with chemotherapy and radiation. What is the prospect for further advances like this if you get your, as Dr.

Varmus calls it, your optimal budget contrasted with your OMB budget?

Dr. KLAUSNER. The announcement that we made yesterday, which was the result of five NIH-funded clinical trials, is an example of the productivity of the clinical trials system——

Senator SPECTER. It was not timed for today's hearing, was it?

Dr. KLAUSNER. It was not.

Senator SPECTER. Well, it should have been.

Dr. KLAUSNER. Coincidence.

Those trials actually demonstrate, as you point out, for locally advanced or regional cervical cancer, that the combination of chemotherapy and radiation therapy results in a 30 to 50 percent reduction in mortality, quite a significant advance. There is no question that it is these sorts of advances, and there are others that I put just from this past year in my written statement, that our clinical trial system, drug development, drug discovery system, will allow us to make.

It is very much, as Dr. Varmus says, that there is a high opportunity to resource ratio that I think we all face.

Senator SPECTER. Well, we compliment you, Dr. Klausner, on that, and I know it is representative of what everybody at the table could be testifying about. That is why we want to back you up.

STEM CELL RESEARCH AND PARKINSON'S DISEASE

I would like to ask, within the limits of the time that we have here, about stem cells and what we have heard with respect to, say, Parkinson's disease. Dr. Gerald Fischbach is the Director of the relevant institute, and we had some testimony at one of the earlier three hearings on this subject where, with some pushing, it had a ballpark figure of being able to conquer Parkinson's—maybe that is an inexact legal term, as opposed to a medical term—in a 5 to 10-year span.

But I would like to hear from you, Dr. Fischbach, what the prospects are with this stem cells research as applied to Parkinson's to finding a cure?

Dr. FISCHBACH. I am very optimistic about the treatment of Parkinson's disease, because we know where it originates and we know the type of cells that are affected, at least initially, in the disease. There has been tremendous progress, both in implantation of cells and using fetal tissue, both in Europe and in this country.

These cells are intercalated into the brain tissue. We have learned how to make them survive over long periods of time, and they seem to serve the function of restoring a missing neurotransmitter.

Senator SPECTER. Dr. Fischbach, I want to get to Alzheimer's before my red light goes on. Could you give me a ballpark figure of how long between now and conquering Parkinson's?

Dr. FISCHBACH. My best guess and my hope is within the next 10 years, and that stem cells will be enormously important in this effort.

STEM CELL RESEARCH AND ALZHEIMER'S DISEASE

Senator SPECTER. Thank you very much.

Dr. Richard Hodes, as to Alzheimer's, same question.

Dr. HODES. Similar to the response you heard regarding Parkinson's disease, in the area of Alzheimer's disease we have over the last years gained enormously in our understanding of the nature of the underlying processes, the cells that are destroyed, and the nature of the process.

I would have to say, in reality there remains a great deal to be learned before we are able to diagnose the disease early enough, and to intervene and prevent a process which involves loss of neurons. The ability to regenerate neurons through stem cells and through growth factors, together with a recent finding that even in the adult brain nerve cells can reproduce, something they were thought not to be capable of—provides a sense of optimism.

In response to Congressional language in this past year, and in collaboration with a number of NIH Institutes an Alzheimer's disease prevention initiative has begun which will substantially expand our efforts to achieve early diagnosis. For example, this year we will begin for the first time a trial designed to prevent the onset of disease, rather than to attempt to arrest or treat disease in its more advanced stages.

We are optimistic that, with the generous increase in budget and its application to scientific opportunities, we will see an acceleration of progress towards treatment and ultimately prevention.

OPPORTUNITIES IN STEM CELL RESEARCH

Senator SPECTER. Thank you very much. My red light is on, so I am not going to ask any additional question for an oral response. But I would appreciate it if each of you would give the subcommittee a written response on what you would hope to achieve from stem cell research. That is going to be a real battleground in the immediate future, and I would hope that we could follow the path with fetal tissue, where we are able to use fetal tissue for research where it was shown the abortions were not performed to get the fetal tissue.

We have the HHS opinion, but this is going to be a real battleground. To the extent we are armed with specifics from the experts, the research scientists, as to what you think you can accomplish, it would be very, very helpful.

[CLERK'S NOTE.—Due to its volume, the above mentioned document has been retained in subcommittee files.]

STEM CELL RESEARCH GUIDELINES

Senator SPECTER. Senator Harkin.

Senator HARKIN. Thank you, Mr. Chairman. I just back you on that. I think it just holds a lot of promise, and I'm glad that we got the ruling that we did. I think it comports with the law, as I said before, that we wrote here. I hope it does not become too much of a battleground. I hope we can proceed on this in a very determined and yet ethical manner, and I believe we can.

But I just think the promise there is so much that we have got to press ahead, and I assume that you are pressing ahead in stem cell research, given the ruling by the counsel—attorneys for the Department.

Dr. VARMUS. Just to respond briefly, since we met last time, we have formed an oversight committee which is going to meet early

in March. We are preparing draft guidelines. As you know, our investigators are not to use Federal funds for stem cell research until those guidelines are in place, fully understood, and we have subjected them to public comment for 30 days.

Senator HARKIN. Yes, but you will have those guidelines out within a couple of months surely?

Dr. VARMUS. Absolutely.

HUMAN GENOME PROJECT

Senator HARKIN. So I will not delay it any further. The only thing I want to state publicly, we have talked about this privately, and that has to do with the Human Genome Project, which as you know I have been a strong supporter of for many years. There has been a lot of information and developments in the private sector regarding the mapping and sequencing of the gene, especially the sequencing.

Again, just from the record, either you or Dr. Collins, to just talk about how you are coordinating with the private sector in this regard. You mentioned it to me once and again I would just like to have some more elaboration on that.

Dr. VARMUS. We have had a conversation. Remember, the private sector is a lot larger than simply the Celera Genomics Company, which we have been hearing about, because there are many other private organizations that are accumulating sequence data but holding them privately, whereas Celera pledges to release data quarterly.

Our interactions with Celera have been very productive, and very recently we announced an agreement to work together to finish the sequence of the fruit fly, Drosophila Monogaster, through a coordinated effort between Celera and our grantees in California and elsewhere. We are continuing to talk to them about the best way to approach the Human Genome Project.

As you know, our 5-year plan has now pushed forward the time at which we expect to have the sequence finished, and we are working with Celera in efforts to try to make the most of the different approaches that are being undertaken. They have taken a very different strategy for carrying out the sequencing, and we think that there is the potential for blending their volumes of data with our more systematic approach in a way that will help both sides and provide more public data.

PATENTING GENES

Senator HARKIN. Should we—how concerned should we be about the whole aspect of the patenting of genes and the implications that this might have for even further research? Is it alarmist or not for some people to be saying, well, with the amount of patenting that is going on, that it is really going to cut down on the amount of research that is needed? Or under the patents that we have will adequate research be allowed or be able to continue under the kind of patenting that is happening right now with the genes?

Dr. VARMUS. Well, these are very difficult issues, Senator Harkin. Our position has been that sequencing—sorry, that patenting of newly isolated genes whose functions and medical importance are identifiable at the time of patenting can be a spur to develop-

ment of the next steps that would benefit the public, and we believe that has been the case in the instance of several recently cloned genes.

We take a somewhat different position about cloning sequence—sorry, patenting sequence at random, a sequence whose functional attributes cannot be ascertained. We have not, for example, at the NIH pursued patent rights for a sequence whose function and medical importance is not known.

Senator HARKIN. Again let me try to sharpen that a little bit. If certain sequencing of genes are patented, could it have a deleterious effect on further research on the use of those genes for, let us say, relieving—for certain medical procedures and stuff? Could it have a deleterious effect?

Dr. VARMUS. Senator, the issues that apply to the patenting of genes are similar to the issues that apply to the patenting of other intellectual property. That is, by providing some patent protection to discoverers and to licensees, we encourage them to develop the fruits of that information for public welfare, but also——

Senator HARKIN. I do not have any problem with that, but in terms of using those genes or the knowledge of the sequencing of those genes for other basic research?

Dr. VARMUS. Yes, I understand that, and that is the balance. That is, in general the sequence information per se is available and the sequence information can be taken advantage of. But the development of specific products would require licensing from the patent holder.

Senator HARKIN. I just, I think it is something, I do not know the answer to it, but I think there may be some real problems out there. I do not want to be alarmist about it, but I just think there are some problems in terms of further basic research that might be clipped, might be stopped or at least not proceed apace because of the patenting.

Dr. VARMUS. You are raising a general issue with respect to research tools that we have taken very seriously at the NIH. We have been looking into ways in which we can ensure that not-for-profit research can proceed even in the presence of intellectual property protection that has a full basis in existing law.

Senator SPECTER. Thank you very much, Senator Harkin.

Senator Stevens.

PROSTATE CANCER RESEARCH PLAN

Senator STEVENS. Thank you.

That is a very interesting subject, Senator Harkin, and I think you have to look at the flow of funds into the research base that comes from the freedom that is involved there. There is a balance, I am sure we all agree.

I would like to chat with you a little bit, Dr. Varmus, about the problem of the report that we directed to be presented to the House and Senate Appropriations Committees within 6 months outlining the NIH's professional judgment for prostate cancer research for the next 5 years. Do you have a team working on that?

Dr. VARMUS. We have a report that Dr. Klausner might want to talk about, that presents a very thorough and excellent plan for prostate research for the next several years.

Senator STEVENS. Has that been done in accordance with the request we made in the last appropriations bill?

Dr. KLAUSNER. Yes, although we are finishing that up for the April 1st deadline, as required in the language.

Senator STEVENS. We will have it in April?

Dr. KLAUSNER. Yes.

Senator STEVENS. That is good. I notice from the outline here that Bettilou has given to me of the way the funds are distributed in your budget for research initiatives and programs that prostate cancer has an increase of $9 million in this budget. We increased it some $55 million last year. Will your report deal with the amount of funds that could be utilized in prostate cancer research?

Dr. KLAUSNER. Yes, it will be, as requested, a professional judgment report.

Senator STEVENS. I do not want to prejudge that, but think that—as you know, last year I had a little battle with the chairman, and he won, about earmarking funds for cancer, prostate cancer research. I am alarmed at the rate or really at the allocation base for prostate cancer research as compared to other cancers. It does seem to me that this is a growing problem.

I think American men are suddenly waking up to the fact that they have been sort of the last pigeonhole, more or less, in the cancer research base.

Can we have a hearing on that report when it is prepared? Would it be best to postpone it until then, Dr. Klausner?

Dr. KLAUSNER. I would be delighted to do that. I think we will be talking to you next week as well about our implementation of a 50 percent increase this year of funds allocated for prostate cancer.

Senator STEVENS. That is this year. I am talking about the budget we have got for next year and there is hardly any increase. It is just not even the rate of inflation for NIH. So I want to make sure that the initiative does not sputter out in terms of what we are doing. But I will wait for the report. I do not think it would be fair. If we ask for a report, we ought to wait for it.

CANCER IN MINORITY POPULATIONS

Let me ask you on another matter, though. Dr. Varmus, my information is that the Institute of Medicine has put out a report that calls on the National Cancer Institute to do more to reduce the incidence of cancer in minority populations in particular. It is sad for me to note that Alaska Natives of all ethnic groups have among the highest mortality rates in the country from cancer, which surprised me.

I know that we have unique problems with our Native Americans, and with the Indian Health Service involved in particular, but have you instituted any programs that deal with reducing those extremely high rates of mortality from cancer as far as the minority population of the country is concerned?

Dr. VARMUS. The Cancer Institute has established an office to focus especially on cancer in special populations, and they have been working closely with the authors of the IOM report. I believe that the recommendations in the IOM report have largely already been responded to, even in the course of preparing the report.

Dr. Klausner might want to comment further about specific programs that address Alaska Natives.

Dr. KLAUSNER. Yes. We have several programs specifically to address these issues, including collaboration with the Indian Health Service, as well as a support for the registry monitoring surveillance system throughout Alaska. This is an essential part of initiating cancer control efforts. There are, again, a variety of new initiatives this year specifically in Alaska and with other Native American populations to use that registry information to initiate local infrastructures for addressing questions such as late diagnosis, and delay between diagnosis and treatment, which is in some part, from previous research, responsible for these altered survival rates which you are referring to.

ACCESS TO HEALTH SERVICES IN RURAL AREAS

Senator STEVENS. If you will permit me just one comment, these people live in an area that is twice the size of Texas, with a population a little over 100,000 people, and to realize that they have trouble getting diagnosis and treatment, you know, is just tautological as far as I am concerned. It is not there. If it is a problem of diagnosis and treatment, I think we ought to collaborate on that and see what we can do.

I do not know of any of the systems that would be available for diagnosis or treatment that is available in that whole area that Alaska Natives live in. This I think may be just one of our basic mistakes in not locating some new high tech diagnostic equipment in places like Nome and Barrow. I mean, if they have got a problem caused by not being able to get down to Anchorage or Seattle for diagnosis and treatment, that problem is geographical. It is not something that is indigenous to their population. It is just where they live.

Dr. KLAUSNER. I think there is a combination of problems as we see in different populations. But you are absolutely right, access to state of the art diagnosis and treatment in rural areas or sparsely populated areas is very difficult in many instances. There are a variety of initiatives with other agencies, including across the NIH, particularly with telemedicine.

It is going to be very difficult to get equipment available directly to everyone. New ways of communicating, new ways of providing that state of the art access without actually being there, are some of the programs that we are involved in, primarily with other agencies as well as with the State.

Senator STEVENS. I look forward to visiting with you on that.

Thank you very much, Mr. Chairman.

Senator SPECTER. Thank you, Senator Stevens.

Senator Cochran.

Senator COCHRAN. Mr. Chairman, thank you.

JACKSON HEART STUDY

Dr. Varmus, we appreciate very much the funding of the Jackson Heart study. This is a program that is going to do special research of a Mississippi population that has unacceptably high cardiovascular disease numbers. The University of Mississippi Medical Center is involved, Jackson State University, and Tugaloo College

in the Jackson area. We have high hopes for that being the basis for some progress in dealing with that very serious problem in our State. We hope that more research can be done in Mississippi, as a matter of fact, on these chronic disease problems in our State.

The center where this study is located was also recently the host of a meeting that Dr. Gorden came down and attended on juvenile diabetes and other diabetes-related health problems. I want to thank him again for being able to be there. It was something that was very warmly received by the medical community in our State.

DIABETES RESEARCH

I am curious to know what the outlook is now, if you can tell us or Dr. Gorden can tell us, on coming up with—I guess in following up the chairman's question on Alzheimer's and Parkinson's—some cures or treatment plans for diabetes that can give hope to the community that has to deal with those serious problems.

Dr. VARMUS. There is a great deal of optimism these days, I believe, in new approaches to diabetes. As you probably know, there is a report about to be issued on new prospects for diabetes research as a result of a working group established by Congressman Nethercutt. Among the things that are outlined, at least one initiative connects to Senator Specter's question about stem cells. It addresses an interest in being able to use stem cells as a means to allow cells to grow in the body of an individual with juvenile diabetes and to produce insulin chronically.

There are advances that have been made in transplantation of pancreatic tissue. Several NIH Institutes are working on means to allow transplantation of such organs to proceed by controlling the immune response to transplants. We believe that transplantation and better control of glucose levels offer two important modalities for improving survival and the reduction of complications for patients with diabetes.

Senator COCHRAN. Let me ask Dr. Gorden, a fellow Mississippian out there. We appreciate very much his presence this morning. What can other NIH Institutes do to become more involved? I know this is not just centered in one Institute. Diabetes research cuts across a number of Institutes. Is there a way to coordinate this more effectively, or can Congress do something that would be more helpful in directing more research in this area?

Dr. GORDEN. First of all, I very much appreciated being in Jackson with you, Senator Cochran. It was a real pleasure.

I think that there are a number of NIH Institutes. One of the models is the special appropriation we received for type one diabetes, which was a trans-NIH effort, and I think it has been a model program in which nine NIH Institutes have participated in a variety of programs related both to, in this particular case, type one diabetes and utilizing many of the technologies that Dr. Varmus has mentioned.

But in addition, I would like to emphasize some of the things that are terribly important. That is, our ability now to inaugurate prevention trials. We have two major national prevention multicenter trials under way in both type one and type two diabetes. I think that what we have learned now from clinical trials in terms of preventing the morbidity of the eye and kidney and nerve com-

plications of diabetes, we can enhance that enormously by these prevention efforts. I think that has really been one of the major new areas of approach.

So we are very optimistic and very encouraged. We are pleased to receive this report and we will certainly move forward with it.

Thank you.

NATIONAL READING PANEL PROGRESS REPORT

Senator COCHRAN. If I could ask Dr. Duane Alexander a question about this reading report. I received a copy just as I came into the hearing room, the National Reading Panel Progress Report. I want to congratulate you and those who have worked with you on this progress report of the National Reading Panel.

We set this up 2 years ago with language in this appropriations bill to try to find ways to analyze research in the physical and developmental problems that cause reading disorders and what can be done about it with new classroom techniques and other initiatives.

Could I ask you how far you think we are now from being able to have classroom-ready techniques and technologies to acquaint teachers and parents with how to diagnose or observe more effectively those with reading problems and then doing something to deal more effectively with those reading problems?

Dr. ALEXANDER. Senator Cochran, it is our hope that the National Reading Panel will be a major step forward in analyzing the research literature that is available to instruct us as we move to more effective instruction of the children in our schools in how to learn to read. The panel has completed a detailed development of methodology to analyze the more than 25,000 articles in the research literature, to assess its quality and evaluate what is ready for application, what has been adequately demonstrated scientifically to be useful and valid.

The recommendations that we expect to come from this panel we hope will provide for education what we talk about in medicine as evidence-based medical practice. We hope that we will bring evidence-based instruction for teaching reading to the schools.

Senator COCHRAN. Thank you.

Thank you very much. I ask that the enclosed letter from Dr. Duane Alexander and the National Reading Panel Progress Report be included in the record of today's hearing, following the exchange between Dr. Alexander and myself.

Senator SPECTER. Thank you, Senator Cochran.

[The letter follows:]

LETTER FROM DR. DUANE ALEXANDER

DEPARTMENT OF HEALTH AND HUMAN SERVICES,
NATIONAL INSTITUTES OF HEALTH,
Bethesda, MD, February 22, 1999.

Hon. THAD COCHRAN,
U.S. Senate,
Washington, DC.

DEAR SENATOR COCHRAN: As you requested, I am pleased to transmit to you the enclosed Progress Report of the National Reading Panel (NRP), which I received today. The Report details the activities and accomplishments of the NRP to date, as well as its plans to complete its charge in early 2000. It has proven to be a major

undertaking, only recently completed, to develop the scientific methodology that now will enable the Panel to systematically assess the research literature on reading and the teaching of reading. The adoption of this methodology by the Panel will enable it, for the first time ever, to use trustworthy scientific evidence to produce recommendations and strategies that can be used directly by educators in the Nation's classrooms.

Highlights of the Panel's Report include:

—The Background Section provides an overview of the reading problems in this country; their societal costs; a history of the so-called "reading wars;" and the importance of reading research to finally move us beyond these counterproductive disputes.

—The second section details how I, in consultation with the Secretary of Education, established the Panel in April of 1998; and provides information on the 14 members of the Panel; and the charge to the Panel.

—Section 3 details the accomplishments of the Panel to date. Specifically, in the ten months since its establishment, the NRP has held five meetings of the full Panel, numerous meetings of its six Subgroups, and conducted five regional meetings across the country to listen to and learn from the many voices of parents, educators, community members, decision-makers, and civic and business leaders.

—The fourth section reviews the lessons learned by the NRP from the 44 invited presenters and 73 members of the public who addressed the Panel at the regional meetings.

—The fifth section deals with the Panel's development of the research methodology it will use to conduct the assessment of the research literature, and details the specifics of the methodology it has adopted.

—The last section lays out the work yet to be accomplished, and the Panel's expectations for its final products to help construct the needed bridge between research and practice.

I will continue to keep you informed of the progress of the Panel as it completes it work.

Sincerely yours,

DUANE ALEXANDER, M.D.,
Director.

Enclosure.

[CLERK'S NOTE.—Due to its volume, the above mentioned report is being retained in subcommittee files.]

Senator SPECTER. Senator Hollings.

CERVICAL CANCER TREATMENT

Senator HOLLINGS. Dr. Klausner, when I saw that headline that you were now having dramatic results on breast cancer with the combination of both radiation and chemotherapy, I was thinking that if I were a doctor I would be embarrassed to announce it. Are you folks so structured and segmented out there that each doctor only tries one cure?

I mean, how about why do you not put in interferon, try all three and see what happens? I mean, how is it that the best brains in medical research come out and finally decide to not just give the radiation, but give the chemotherapy along with it?

Dr. KLAUSNER. There actually have been other combination therapy attempts which did not show an advantage. In fact, it was one particular drug, Cisplatinum, that was the critical thing in combination with the radiation therapy. So this was part of a very long and I think quite logical process of trying different drugs, different combinations.

Previous results suggested that the combination of chemotherapy and radiation was more toxic but no more effective. So it is not just adding more. What we have now actually developed from smaller trials, demonstrating the value of using drugs that act by different

mechanisms. In this particular type of cell, the cervical cancer cell that has spread, apparently the type of DNA damage caused by the platinum-based compound is a particular sensitizer to radiation.

Senator HOLLINGS. It is just not simple chemotherapy and radiation by itself.

Dr. KLAUSNER. I appreciate your point, but I think it is more complicated and it does take time through these clinical trials to find out which dose, which drugs, which combination, what order, maximizes the outcome and minimizes the toxicity.

PREVENTION RESEARCH

Senator HOLLINGS. What amount of your budget goes to prevention research?

Dr. KLAUSNER. It of course depends how prevention is defined. In terms of trying to understand the causes of cancer, which we think is an essential part of prevention research——

Senator HOLLINGS. Right.

Dr. KLAUSNER [continuing]. As well as direct interventions for prevention from behavior to new drugs to prevent, about $500 million out of the $2.9 billion.

Senator HOLLINGS. The reason I ask is that we have got some dramatic initiatives down in my own back yard with respect to prevention and they have now associated the cancer center there at the Medical University of South Carolina along with the American Health——

Dr. KLAUSNER. Yes.

Senator HOLLINGS [continuing]. In New York, and we find out that American Health has just got backed up all kinds of wonderful research without any clinical trials. We have got the opportunity for all the clinical trials that you could possibly think of, because we are number one. Listening to Senator Stevens, we are number one in breast cancer, cervical cancer deaths. In fact, with prostate we find that, with our minority, our black population, it is an accelerated type cancer whereby you have got a chance with, let us say, white folks; with black folks, once discovered you have got no chance at all. It just goes right through the system.

We find such discrepancies out from the surveys that the Medical University and medical professionals are conducting in South Carolina. The University now has a van that travels around a large part of the State, conducting screenings for heart disease and diabetes and everything else, and also taking these surveys from the North Carolina line to the Georgia line. We are finding out a heck of a lot of good research, as well as providing important treatment, particularly to the minority population of my State, which normally is too scared or hesitant to get screening in the first place or too poor to pay a doctor to treat them if screening does turn up something.

This program promises to be a great success. The local churches and community leaders support it. But I think we have got to do more in the way of prevention because in my opinion we could be saving even more lives and detecting cancer more frequently. Dr. Klausner, I look forward to talking to you more about this.

Dr. KLAUSNER. I fully agree with you. Let me just say, we are very pleased about this new arrangement between the NCI-funded

cancer center in New York and the Medical University of South Carolina. We agree with you. We have been very involved in this and we think this is going to be a great opportunity for expanding activities on both ends.

Senator HOLLINGS. Thank you very much. Thank you, Dr. Varmus.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Hollings.

Thank you all. This is an extraordinary group. We really deeply appreciate your work. We have put the congressional money where our praise is and we intend to do more of that.

Thank you, and that concludes our hearing.

PREPARED STATEMENT OF SENATOR LARRY CRAIG

We have received a prepared statement from Senator Larry Craig, we will have it inserted into the record at this point.

[The statement follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Mr. Chairman, I would like to thank you for holding this hearing today on the President's budget requests for the National Institutes of Health and the Department of Health and Human Services. I sincerely appreciate the time each of you has spent on expressing the importance of the funding for each particular department and more specifically the multitude of diseases that plague so many.

In staying within the confines of a balanced budget we are faced with a difficult challenge, making it more important than ever that we get our priorities straight. The testimony of our witnesses today will be very helpful in that process of priority-setting and goal setting for a balanced budget.

Again, I would like to thank the chairman and our panel of witnesses here today. The information you provide will be of great assistance to us as we consider the funding levels appropriated to the Departments of Health and Human Services and the National Institutes of Health.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Institute for response subsequent to the hearing:]

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

FUNDING OF RESEARCH PROJECT GRANTS

Question. You are proposing to provide no inflation adjustments for non- competing awards. Does the average investigator with an ongoing project have to make cutbacks in the scope of research when faced with this circumstance?

Answer. With the average non-competing direct cost budget in fiscal year 1999 at approximately $200,000, the loss of the 3 percent adjustment for inflation factor would be $6,000. We do not believe that NIH-supported research investigators will be adversely affected by this action.

Question. What other effects are likely to be felt from this decision?

Answer. The ability to support non-competing awards at the committed levels has been the cornerstone of NIH's financial management plan and has been a significant component of our ability to stabilize the level of funding of research project grants. Not providing inflation adjustments might affect the way in which applicants develop budgets in the future.

MINORITY CANCER RESEARCH

Question. What is the NCI fiscal year 2000 budget request for minority cancer research?

Answer. The NCI fiscal year 2000 budget request for minority cancer research is estimated at a funding level of $144,000,000.

Question. How does the proposed $30 million for minority cancer leadership initiatives break down? Is it $30 million per year?

Answer. It is anticipated that NCI will support this leadership initiative with $5 to $6 million per year for a five-year period.

Question. If not, over how many years?

Answer. NCI anticipates that it will support this leadership initiative over a five-year period.

Question. What will the $30 million fund?

Answer. This new minority cancer leadership initiative is intended to create and maintain an infrastructure that will support a variety of community-based cancer awareness, prevention and control activities, foster collaborations between established researchers and minority/underserved communities, and enable investigators from these communities to compete successfully for research support. The Initiative involves three phases: (1) Infrastructure-Capacity Building; (2) Establishment of Academic/Clinical Partnerships, and (3) Development of Grant Applications with Partners. Initial funding decisions will be based upon an applicant's demonstrated level of readiness, geographic and ethnic diversity, and scientific merit and activities initiated during each phase will continue for the entire award period. NCI anticipates being able to fund 8 to 10 leadership grants with this allocation. We are unable to be more specific at this time because the initiative may provide support for large projects (with a primary office and one or more regional units) or small-scale projects involving a single site. Funding levels for projects in the former category might, for example, include support for 2–3 FTEs in the primary office, 4–5 FTEs at each regional unit, and additional monies for facility cost, supplies, travel, and meeting support. Funding for small-scale projects would include support for 2–3 FTEs, facilities costs, supplies, travel, and meeting support. All applicants must set aside travel funds for PI's, Research Directors, and other key staff members to attend annual meetings to be held in Bethesda, Maryland.

Question. How does that funding level compare with the funding level provided for the original minority cancer leadership initiatives?

Answer. The funding levels (dollars in thousands) for the original minority cancer leadership initiatives are as follows:

Fiscal year	*Amount*
1995	$5,219
1996	3,344
1997	4,126
1998	5,047

The funding levels are comparable to those levels in the past and the NCI is committed to continuous support of the leadership initiative.

Question. Is the Office of Research on Minority Health funding included in the proposed $30 million?

Answer. The NCI Network initiative will be funded independently of the ORMH.

Question. Can we receive, within 60 days, a plan from NCI and NIH to implement the IOM recommendations?

Answer. The NCI staff is currently evaluating the IOM Report and its recommendations in detail. NCI takes this report seriously and will give it careful consideration in the context of its ongoing and planned initiatives for minority and medically underserved populations. Before the recommendations are implemented, however, NCI plans to convene a Special Populations Working Group to further assist it in evaluating the recommendations and formulating a response and implementation plan. We intend to convene this Special Populations Working Group within the sixty-day time frame cited.

Question. Can we expect revised budget requests for NCI and NIH to address IOM findings on funding inadequacies and recommendations for increases in certain programs?

Answer. Any revision in NCI budget requests in the future will be based on the findings, recommendations and implementation plan formulated with the assistance of the Special Populations Working Group.

EVALUATION SET-ASIDE

Question. Section 241 of the Public Health Service Act allows the Secretary to use not more than 1 percent of any appropriations authorized under the PHS Act for the evaluation of the implementation and effectiveness of the PHS programs. The fiscal year 2000 request proposes to raise the limit to 1.5 percent. The funds are

used both internally by NIH institutes to evaluate their programs, and are a major source of funding for the Agency for Health Care Policy and Research (AHCPR) and the National Center for Health Statistics (NCHS) within CDC. In fiscal year 2000, it is proposed that a very large part of AHCPR's budget, and all of the NCHS budget, come from the evaluation set-aside. The proposed increase would amount to an additional $80 million that NIH would devote to evaluation activities. How much does NIH spend overall on evaluation activities?

Answer. The table below reflects the amount spent by NIH on its own evaluation activities and in total in fiscal year 1998 and fiscal year 1999 and an estimate for fiscal year 2000:

ONE-PERCENT EVALUATION SET-ASIDE

[Dollars in thousands]

	Fiscal years—		
	1998	1999	2000 estimate
NIH	5,500	6,500	2,830
Total	104,445	123,574	227,697

Question. Of the evaluation set-aside, how much is used by NIH internally, and how much goes to support the shared resources represented by AHCPR, NCHS, etc.?

Answer. In fiscal year 2000, the AHCPR share would increase by 153.7 percent over fiscal year 1999 and would amount to 57.4 percent of the set-aside. Similarly, the NCHS share would increase by 59.7 percent over fiscal year 1999 and would amount to 35 percent of the set-aside. It is estimated that the NIH share would decrease from $6.5 million in fiscal year 1999 to $2.8 million in fiscal year 2000 due to the lower amount of funds available after the 1.5 percent set-aside; however, the exact distribution of the total one-percent evaluation funds not used to support NCHS or AHCPR has not yet been determined.

Question. What direct benefits does NIH derive from the external activities supported with the evaluation funds?

Answer. NIH benefits from the availability of the major national statistical systems run by NCHS which track changes in health status and the provision of health care; assess the effectiveness of public health programs; and identify health problems, risk factors, and disease patterns in the U.S. For example, NCHS supplies the cancer mortality data used by the National Cancer Institute for the annual cancer statistics reviews produced by its Surveillance, Epidemiology, and End Results (SEER) Program. NIH also benefits from the availability of studies and surveys supported by AHCPR that track medical expenditures and conduct research on improving the quality of health services, in order to help bridge the gap between what the medical scientists know and the actual health care delivered to patients and the community. Likewise, evaluations of the impact of crosscutting public health initiatives prepared by the Office of Public Health and Science (OPHS) and the Office of the Assistant Secretary for Planning and Evaluation (OASPE) are valuable to NIH, as well. All of these data sources and health services research studies serve as important inputs and feedback mechanisms to NIH that help it to direct and assess the effectiveness of its basic and applied research and prevention activities across many disease areas.

Question. What benefits will NIH see from increasing the set-aside to 1.5 percent, which will add almost $80 million to NIH's amount?

Answer. The benefits do not vary with a change in the percentage of the evaluation set-aside. All of the above activities are important to support, and because of the tight budget caps, their funding requests would have been reduced by about $100 million if the limit on the evaluation set-aside was not increased in the President's budget proposal.

NIH RESEARCH PRIORITY SETTING

Question. The fiscal year 1998 Labor/HHS Appropriations Act mandated that a comprehensive study on NIH research priority setting be conducted by the Institute of Medicine (IOM). The study, entitled Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health, was released on July 8, 1998. The study made 12 recommendations relating to allocation criteria the decisionmaking process, mechanisms for public input and the impact of congressional directives. The study particularly stressed that NIH needs to engage the public to a greater extent in informing the process of research priority

setting. In response, NIH is setting up two types of bodies: (1) a Council of Public Representatives to give disease advocates greater access to the NIH policy-making process; and (2) Offices of Public Liaison in each of the individual institutes and the NIH Director's office. What are the responsibilities of the Council of Public Representatives and how will the Council's work and contributions be integrated into the NIH policymaking process?

Answer. In order to obtain some public views about the roles, responsibilities and composition of the Council of Public Representatives (COPR), I held a public meeting on September 23, 1998. This meeting was useful in revealing the many ways the COPR can have an impact upon NIH. The primary roles of the COPR will be to (1) bring public views to NIH activities, programs and decision-making, (2) take information about NIH's progress and processes out to an even broader public, and (3) look at NIH's operations and help us evaluate performance. To elaborate somewhat, the COPR will be a public forum for discussing important issues, for example, NIH priority setting, clinical trials and managed care, privacy and genetics, health disparities among various populations, and many other matters that have an impact upon the public. We also hope that the COPR membership, people from all walks of life and based around the country, will help us communicate better with broad public audiences about NIH and help provide us even more public perspective. In addition, we expect that COPR will help us review NIH priorities and current mechanisms for public input to NIH decisions. The COPR has been chartered as an advisory committee under the Federal Advisory Committees Act. I am looking forward to the first meeting of the COPR, which will occur in the Spring, and to working with the COPR over time, because I think this group has the potential to have a significant impact upon how NIH operates and makes decisions across a broad spectrum of activities and programs.

OFFICES OF PUBLIC LIAISON

Question. What are the responsibilities of the new Offices of Public Liaison and how do they differ from the current Office of Public Affairs (or Public Information or Public Inquiry) in each of the institutes and Centers?

Answer. Offices of Public Liaison have been established in each Institute and Center (if they did not already exist) and in the Office of the Director. In the Office of the Director, the current Office of Communications has been reorganized and renamed the Office of Communications and Public Liaison (OCPL). The possible functions of all of the offices of public liaison (OPLs) were discussed with 23 public representatives who met with me on September 23, 1998, to discuss the issue of enhancing public participation in NIH activities. Core functions of the Institute-level OPLs discussed at this meeting include: conducting outreach to constituency groups and serving as a contact point for the public (especially with regard to policy matters) and place where Congress can refer its constituents. Several additional activities for the OPLs were suggested: educating the public about research, carrying out activities recommended by the new Council of Public Representatives (COPR) , and identifying public concerns and bringing them to the attention of the COPR. The OPL at the NIH level has some additional responsibilitiesit will staff the meetings and other activities of the COPR, work on an ongoing basis with the institute-level OPLs to help share "best practices" for enhancing public participation in NIH activities, evaluate NIH's performance on "outreach" and public liaison activities, and, where appropriate, suggest additional activities. Each of the Institutes and Centers also has a communications office. In many cases, the new offices of public liaison have been combined with the standing communications offices. These communications offices have concentrated primarily on (1) health education programs to bring science-based health information to the public and (2) media relations to help mass media outlets convey the results of new research to the public accurately and in a timely fashion. These offices have also been involved in helping to recruit patients into clinical trials, responding to millions of public inquiries (primarily about disease problems), using the new electronic technology to reach certain audiences, devising strategies to reach specialized audiences (such as Spanish-speaking populations, individuals with low reading ability) with important health messages, and in some cases creating science education programs for students.

MINORITIES AND CANCER

Question. What progress has been made in delineating an overarching strategy to guide efforts in studying ethnic or socioeconomic differences in cancer rates across NIH?

Answer. NCI acknowledges the need to expand and enrich our surveillance programs. Work is in progress to enhance our capacity to measure the national cancer

burden and to speed our progress to reduce its impact on all Americans. This effort includes clarifying the basis of differences in cancer rates among people of various ethnicities and of varying socioeconomic strata. We are also studying differences in quality of cancer care among those groups and its impact on mortality. We have consulted a group of experts in surveillance to help us tackle these complex issues. The Surveillance Implementation Group has met several times over the past year, and we expect recommendations addressing these questions in the near future. We have also recently hired a demographer with expertise in health data for racial/ethnic populations to help direct surveillance efforts.

The scope of the NCI surveillance enterprise includes a broad and complex range of data and data systems designed to measure the cancer burden. In addition to SEER's coverage of cancer incidence and survival for 14 percent of the U.S. population and significantly larger proportions of most racial/ethnic groups, the NCI utilizes and publishes reports based on National Center for Health Statistics (NCHS) data on cancer mortality for the entire U.S. population. Specially funded NCI surveys, cooperative group consortia, data linkages with national databases, and supplements to federal health surveys are mechanisms we use to provide information on cancer risk, health behavior and health status, patterns of care, cancer outcomes, cost and quality of cancer care, and quality of life. Every surveillance research and analysis project includes an emphasis on information for different populations. Selected examples are the 1998 SEER monograph on prostate cancer, which includes a special chapter devoted to racial/ethnic patterns, as well as the ongoing longitudinal SEER Prostate Cancer Outcomes Study which oversampled black and Hispanic men.

The NCI recognizes the need to better explain the disparities in the cancer burden in several high-risk ethnic minority and medically underserved populations and is emphasizing research which reflects diversity of the U.S. population. In 1975, 1979, 1983, and 1992, SEER expanded to include populations critical to explaining the burden of cancer in this country. These expansions have increased the coverage of Hispanics, urban blacks, and Asian and Pacific Islanders in Southern California and the South San Francisco Bay Area, rural African-Americans in Georgia, northwestern populations in Seattle, Arizona Indians, and Alaska Native Americans. One of the recommendations of a group of experts convened by the NCI to review its entire cancer control effort (the Cancer Control Review Group) is that we expand coverage to capture additional key populations, such as rural low-income whites, more diverse American Indian populations, rural African-Americans, and additional Hispanic subgroups. Beyond the SEER Program, the Cancer Surveillance Research Program is planning a coordinated effort cofunded by other NIH agencies (such as the National Heart, Lung, and Blood Institute and the NCHS) to improve data collected on mortality by race/ethnicity.

NCI-sponsored investigators are emphasizing studies of screening among traditionally underserved populations, and our Cancer Surveillance Research Program is addressing the measurement and monitoring of cancer rates based on SES indicators at the level of the individual and based on that person's neighborhood and community characteristics. The Cancer Research Network, the SEER-Medicare-linked database, and the Breast Cancer Surveillance Consortium are also being used to enhance our health services and economics research.

Question. What adjustments have been made in the NCI budget to respond to the IOM report recommendation for increased funding of studies on cancer in ethic and medically underserved groups?

Answer. We have not made adjustments in the NCI budget as yet, pending analysis of the IOM report and its recommendations by the Special Populations Working Group.

Question. How will NCI respond to the IOM report recommendation to expand the number of ethnic minority investigators in cancer research and increase the representation of ethnically diverse researchers and public representatives serving on NCI advisory and program review committees?

Answer. The NCI has recently established the Comprehensive Minority Biomedical Branch (CMBB) within the Office of Centers, Training, and Resources of NCI. This new unit focuses on a broad-based approach to dealing with every aspect of the ethnic minority cancer problem, with particular emphasis on the cancer incidence and mortality disparity between ethnic communities and the general population. Specific emphasis is given to increasing funding for research by minority scientists, the enrollment of minority physicians and patients into clinical trials programs, training and manpower development of minority students and faculty, and the building of extensive networks and partnerships between the federal funding community and academic research communities. Importantly, the CMBB has created a new training initiative, called the CURE Program (Continuing Umbrella of

Research Experiences) for underserved minorities. This initiative begins by exposing promising minorities at the high school and undergraduate levels to cancer research and then provides a continuum of competitive opportunities through the successful established independent cancer investigator. An aggressive marketing plan for the CURE program has been developed which involves site visits, presentations at scientific meetings, a quarterly newsletter, flyers, buttons, and electronic media dissemination. A tracking system for CURE will be in place to evaluate the success of this program.

In addition to the CMBB and its CURE program, NCI is promoting the entry of ethnic minority investigators into the research community through its new initiative, the Special Populations Network. A major goal of the Special Populations Network is the promotion of training opportunities, including mini-sabbaticals for minority students/scientists, and enhancing awareness and utilization of training opportunities. To enhance training opportunities for minority scientists, awardees will identify junior minority researchers and students participating in the network and facilitate their pursuit of further training assignments in cancer control and related areas. Awardees will also arrange short-term training assignments for minority researchers in cancer prevention and control in the programs of the NCI and at NCI-funded cancer centers. Awardees are expected to demonstrate that they are taking advantage of training opportunities offered by NCI (e.g., the CURE Program or other grant mechanisms) or by other appropriate organizations. Awareness of NCI training opportunities will be enhanced by establishment of informational links with the CMBB. Utilization rates of NCI training opportunities will be tracked annually with the assistance of the CMBB.

NIH ACCOUNTABILITY

Question. What plans do you have for responding to the IOM recommendation that NIH set up a regular reporting mechanism to increase NIH accountability to the U.S. Congress and public constituencies?

Answer. As a steward of public funds, the NIH fully recognizes its accountability to the American public. While there have always been formal and informal interactions with all of the publics that are involved with, or affected by, NIH's research and activities, this has been variable and is being more systematically addressed through a variety of mechanisms. These include ongoing efforts to solicit the views of many individuals and groups, including the extramural scientific community, patient advocacy groups, Congress, the Administration, and NIH staff. For example, each Institute and Center (IC) convenes meetings of national advisory councils or boards, with members from the public, medical, and scientific communities, to review a broad range of IC policies, and many conferences and workshops are organized each year to gather opinions on specific scientific, health, ethical, and administrative issues.

To broaden the interactions among the public, medical and scientific communities, patient advocacy groups, and others, the NIH Office of the Director and Institutes and Centers have undertaken several steps to provide the public with more opportunities to present their views and receive information about NIH research activities. An Office of Public Liaison has been established in the Office of the Director and in each Institute and Center. These offices are points of contact for interested parties to reach NIH to address their concerns and questions about research that NIH conducts. A Director's Council of Public Representatives has also been established and will serve as an important conduit of information from and to the public about NIH programs.

Input from the public on research goals will also be gathered through the development of strategic plans by each NIH Institute and Center. These plans will articulate each Institute and Center's overarching vision or mission, establish research priorities, delineate their planning processes, and describe existing scientific opportunities and their initiatives/plans for capitalizing on them. This is the kind of strategic planning that takes place at the NIH and is being expanded. The NIH Director has requested that each IC develop a 2–5 year strategic planwith input from a wide range of NIH constituents, including patient and other health advocates, scientists, health care providers, Congress, the Administration, NIH staff, and other representatives of the public.

In addition, the NIH Director will involve his Advisory Committee and the new Council of Public Representatives in assessments of NIH's research program under the Government Performance and Results Act and in discussions of the public policy, e.g., privacy of research records. The ACD membership has also been expanded by three, and these vacancies will be filled by additional public members.

PROSTATE CANCER

Question. To what extent have the recommendations of the Prostate Cancer Progress Review Group been incorporated into the NIH and NCI research agenda for fiscal year 1999 and planning for fiscal year 2000?

Answer. The NCI's Prostate Cancer Progress Review Group (PRG) submitted its final report, containing a comprehensive, prioritized list of research priorities, in August 1998. The report, entitled "Defeating Prostate Cancer: Crucial Directions for Research," can be found on line at http://www.nci.nih.gov (click on "What's New"). The PRG's report was eminently successful in providing us a clear, thoughtful vision of where we want to be and how we want to get there, and we were able to enthusiastically respond to and address many of the PRG's recommendations. NCI is using the report as a blueprint detailing what the Institute needs to prioritize and fund in order to answer key scientific questions. At this time, NCI is putting into place the mechanisms that will allow them to respond to—and implement, as appropriate—the PRGs' recommendations. For example, NCI funding for prostate cancer research will increase around 50 percent during fiscal year 1999, to a total level of about $130 million. NCI is currently planning to fund over twenty initiatives that are related to the prostate PRG that will allow them to direct funds and to make sure that there are opportunities to address these issues for what is expected to be a rapidly growing prostate cancer research community.

Descriptions of some of the new and ongoing initiatives that will enable NCI to address, or begin to address, the PRG's recommendations can be found at http://www.nci.nih.gov/prostate.html. Some highlights of efforts found in this document which are expected to be fully implemented in fiscal year 1999 include:

Director's Challenge For Molecular Diagnostics.—The NCI Director has challenged the research community to revolutionize our classification of human tumors. Although detection technologies have advanced to the point where we can identify tumors at earlier stages, we currently do not have the ability to classify those tumors based on tumor behavior, prognosis, and sensitivity to treatment. Nowhere is the need for improved classification greater than in prostate cancer. Despite the prevalence of apparently malignant change in the prostates of asymptomatic men, these abnormalities do not always represent aggressive, potentially deadly cancers; we are currently unable to predict which patients should be treated aggressively and which do not require radical treatment. The Director's Challenge will enable us to combine technological advances in molecular detection with rapidly advancing knowledge of tumor biology in a manner that will provide more sophisticated classification of cancer based on molecular criteria.

Early Detection Research Network.—The NCI intends to establish a multi-institutional consortium to develop sensitive and specific tests for the early detection of cancer. This Network will link centers of expertise in tumor biology, diagnostics technologies, and clinical-trials methodology in academia and industry to develop high-throughput assays suitable for clinical testing. The Network will have the capacity to establish estimates of the operating characteristics of candidate assays as early-detection tools. NCI intends prostate cancer to be one focus of activity within the new Network; the current interest in the prostate-specific antigen (PSA) demonstrates the feasibility of this approach. To expedite the discovery and development of more sensitive and specific markers for early disease, NCI will also establish links between activities of the Network and programs in academia and industry that are developing libraries of all known secreted proteins in mammalian cells.

Prostate Cancer Tissue Bank.—Successful development of molecular diagnostics depends on availability of tumor tissue specimens. NCI plans to develop a national prostate cancer tissue resource, possibly modeled after its successful Cooperative Breast Cancer Tissue Resource. NCI is also considering a pilot project to test the feasibility of prospective collection and storage of frozen specimens. In addition to tumor specimens, this resource will contain clinical outcome information to allow correlation between molecular test results and outcome. The design of this registry will provide robust protection of patient confidentiality.

The research agenda at the NIH level has been positively impacted by the PRG recommendations. A trans-institute initiative was recently released between the National Cancer Institute (NCI), the National Institute of Digestive and Diabetes and Kidney Diseases (NIDDK) and the National Institute of Aging (NIA). This initiative is in direct response to a strong call by the PRG to increase our fundamental understanding of the normal biology of the prostate which is considered a real hindrance to progress.

In short, NCI has taken the recommendations of the Prostate Cancer Progress Review Group very seriously. They have begun implementing a number of the recommendations, and it is expected that the report will be a guiding force in our sci-

entific prioritization and planning in fiscal year 1999 and for several years into the future.

Question. What are the "key gaps in the research agenda" and "major new opportunities" identified by the Prostate Cancer Progress review Group and how have NIH and NCI addressed these findings in the plans for research in the coming months and years?

Answer. The National Cancer Institute convened a Prostate Cancer Progress Review Group (PRG) to assess the current research portfolio and identify gaps in our knowledge of prostate cancer that must be filled if we are to conquer this devastating disease. These gaps range from understanding the basic biology of the prostate and prostate cancer to assessing risk factors to developing treatment methods 1 and improving quality of life for men with prostate cancer. The deficits in our knowledge are large. At the same time, we recognize that inherent within each "gap" is an opportunity—an opportunity for discovery, an opportunity for increased knowledge, an opportunity to build on what we already know to take crucial steps forward in defeating prostate cancer.

Although increased support in all areas of prostate cancer research is important, the Prostate PRG identified several areas in which increased support is particularly crucial. These include:

Biology of the Normal Prostate.—We still know very little about the development and biology of the normal prostate; such knowledge will enable us to better understand the changes that can lead to prostate cancer. Responsive NCI Activity: The NCI, the National Institute for Diabetes and Digestive and Kidney Disorders (NIDDK) and the National Institute of Aging are publishing a joint Program Announcement seeking research on the biology of the normal prostate.

Availability and Validation of Animal Models.—Laboratory and clinical models are critical for defining the mechanisms of prostate cancer progression and for testing preventive and therapeutic regimens. Yet only a few such models have been developed, all of which are encumbered by insufficient biological knowledge of the human cancer they aim to simulate. A better understanding of the basic biology of human prostate cancer will accelerate and refine the process of model development. In response, NCI has initiated a new Animal Models Consortium, within which researchers will create models for the development of normal tissue, early cancer, and metastatic cancer. We have begun soliciting proposals from potential participants; the response has been heartening and exciting. We fully expect to receive a number of applications relevant to prostate cancer; if we do not, we may reach out with additional funding to ensure that the Prostate PRG's recommendations are met.

Tissue Banks.—Successful research, in many cases, depends on availability of tumor tissue specimens, but such specimens are all too frequently unavailable to the research community. NCI plans to develop a national prostate cancer tissue resource, possibly modeled after its successful Cooperative Breast Cancer Tissue Resource. We are also considering a pilot project to test the feasibility of prospective collection and storage of frozen specimens. In addition to tumor specimens, this resource will contain clinical outcome information to allow correlation between molecular test results and outcome. The design of this registry will provide robust protection of patient confidentiality.

Validation of Biomarkers for Early Detection, Diagnosis, and Prevention of Cancer.—Despite the prevalence of apparently malignant change in the prostates of asymptomatic men, these abnormalities do not always represent aggressive, potentially deadly cancers; we are currently unable to predict which patients should be treated aggressively and which do not require radical treatment. The identification and validation of biomarkers that can help us predict with accuracy the behavior of a given tumor at the molecular level will help us address this issue. In response to this need, NCI is establishing a multi-institutional consortium, the Early Detection Research Network, to develop sensitive and specific tests for the early detection of cancer. This Network will link centers of expertise in tumor biology, diagnostics technologies, and clinical trials methodology in academia and industry to develop high-throughput assays suitable for clinical testing. The Network will have the capacity to establish estimates of the operating characteristics of candidate assays as early-detection tools. NCI intends prostate cancer to be one focus of activity within the new Network; the current interest in the prostate-specific antigen (PSA) demonstrates the feasibility of this approach. To expedite the discovery and development of more sensitive and specific markers for early disease, NCI will also establish links between activities of the Network and programs in academia and industry that are developing libraries of all known secreted proteins in mammalian cells.

Training in Prostate Cancer Research for Investigators Across the Span of Their Careers.—The PRG placed a very high priority on increasing training opportunities in prostate cancer. NCI has developed several new mechanisms to support training

overall. The Mentored Clinical Scientist Development Program Award (K12) provides funding between the time an investigator leaves the mentored environment and award of his or her first grant, and the Midcareer Investigator Award in Patient-Oriented Research (K23, K24) provides protected time for clinical and population-based research. Another award (K01) allows longtime investigators to "change directions" at midcareer and try a new area of science.

Clearly, the recommendations of the Prostate Cancer PRG form an integral part of our scientific prioritization and planning over the next several years. Although gaps in our understanding of prostate cancer exist, it is certain that by bridging these gaps, we will make real and tangible progress against prostate cancer.

A full enumeration of the gaps and opportunities facing the NCI in the area of prostate cancer research can be found in the PRG's final report, "Defeating Prostate Cancer: Crucial Directions for Research." This report can be found at http://www.nci.nih.gov (click on "What's New"). In addition, we are currently putting into place the mechanisms that will allow us to respond to—and implement, as appropriate—the PRGs' recommendations. Descriptions of some of our new and ongoing initiatives that will enable us to address, or begin to address, these recommendations can be found at http://www.nci.nih.gov/prostate.html.

PARKINSON'S DISEASE

Question. What is the status of the Parkinson's disease research program throughout NIH?

Answer. NIH supports a vigorous and expanding program of research in Parkinson's disease, and has taken significant steps to implement the Morris K. Udall Parkinson's Disease Research Act. This is a time of growing enthusiasm, new directions, and new initiatives for Parkinson's disease research, so that the initiation of activities contained in the legislation is extremely timely. Research activity conducted and supported by the NIH in this area is leading to the reporting of new and intriguing findings.

The NIH is committed to establishing up to ten Research Centers of Excellence to expand and carry forward recent advances in Parkinson's disease research. The National Institute of Neurological Disorders and Stroke (NINDS), the lead NIH Institute for Parkinson's disease, has issued two Requests for Applications (RFA) for these Centers. NIH is making special efforts to attract new investigators—many from other fields of research—to stimulate research on Parkinson's disease.

Discussions have begun between NINDS staff and other organizations, including Parkinson's disease voluntary groups, to consider relevant studies that would be effective in providing Parkinson's disease data while protecting patient and family privacy. Discussions also have been initiated with the National Institute on Aging and the Department of Veterans Affairs to determine the viability of collaborative efforts to establish a Parkinson's disease data system. This year, NINDS has initiated the first phase of a national education program for Parkinson's disease. Its purpose is to develop and communicate important public health messages which will enhance knowledge and understanding of Parkinson's disease. NINDS is also planning to establish an information clearinghouse on Parkinson's disease and stroke.

Coordination among the NIH institutes is essential to build on recent advances and minimize duplication of research effort. Many scientific disciplines and clinical approaches can usefully be brought to bear on Parkinson's disease. To address these issues, other Institutes and Centers (ICs) of the NIH have made Parkinson's disease a focus of research interest. These include: the National Institute on Aging, the National Institute of Mental Health, the National Institute of Environmental Health Sciences, the National Human Genome Research Institute, the National Institute on Drug Abuse, the National Institute of Diabetes and Digestive and Kidney Diseases, and the National Center for Research Resources. In the coming year, NIH will enhance the coordination among interested components, building on the successful operation of the Parkinson's Disease Coordinating Committee. The Committee, led by NINDS, includes representation from the Aging, Mental Health, and Environmental Health Institutes.

Question. What is the status of the Morris K. Udall research centers and awards programs?

Answer. The NIH is committed to establishing up to ten Research Centers of Excellence to expand and carry forward recent advances in Parkinson's disease research. The National Institute of Neurological Disorders and Stroke (NINDS) issued two Requests for Applications (RFA) for these Centers. We were encouraged by responses received from many of the major medical centers in the country. Three Centers received superior scores in review from the first RFA, and were selected for immediate funding in fiscal year 1998. In response to recent research progress and op-

portunity, and in an effort to intensify and expand basic and clinical research in Parkinson's disease, an updated RFA has been issued, with the intent of supporting up to five more Centers in fiscal year 1999. We will evaluate opportunities for further expansion in fiscal year 2000.

While each Center's individual projects will focus on specific aspects of Parkinson's disease research, the goal is to establish a comprehensive program addressing the major research issues. Clinical studies may focus on specific therapies such as surgical ablation and deep brain stimulation, cell implantation, gene therapy, and novel pharmacological approaches. Identification of families with high incidence of Parkinson's will facilitate further genetic studies. Applicants for Center funding are encouraged to propose a full range of studies of normal and diseased brain function relevant to the pathogenesis and course of Parkinson's disease. Finally, development or refinement of resources such as improved imaging technology and animal models will be supported through this mechanism. The Centers will foster an environment that promotes interaction among investigators in a multidisciplinary setting, leading to a better understanding of Parkinson's disease as well as improved diagnosis and treatment. The currently funded Centers are conducting research on several of these objectives: one includes research projects on deep brain stimulation and the development of an animal model; another is focusing on proteins implicated in Parkinson's disease and animal models; and the third is concentrating on the roles that the genes for three proteins associated with Parkinson's disease play in the death of nerve cells.

Question. How many genes related to Parkinson's have been identified to date? What are the implications for improved treatments of this condition?

Answer. With NIH support two new genes have been identified that provide clues to the pathogenesis and mechanisms of Parkinson's disease (PD). A collaboration sponsored by NINDS and the National Human Genome Research Institute (NHGRI) for the first time showed that a single gene alteration on chromosome 4 could cause PD. Although of unknown functions, the protein (alpha-synuclein) encoded by this gene had been identified previously in several different contexts: as a protein found at synapses, the site of information exchange between nerve cells; as a protein linked to memory and learning; and, most intriguingly, as a protein whose fragments are found in the deposits of aggregated protein "amyloid plaques" characteristic of Alzheimer's disease. In a follow up study, scientists demonstrated that synuclein is also located in structures known as Lewy bodies, found in the most common, non-inherited form of PD, and in certain other neurological diseases. This finding supports the idea that inherited PD may provide insights about the more common forms of the disease. The finding also complements a growing body of evidence that abnormal aggregations of proteins, such as those found in Lewy bodies of PD, amyloid plaques of Alzheimer's, and the "nuclear inclusions" in Huntington's disease, are not just disease markers but actively harmful in damaging the brain. Stopping or slowing the formation of these aggregations may present an entirely new approach to preventing the death of brain cells in neurodegenerative diseases. NINDS and NIA are actively supporting research in this area.

A new genetic mutation located on chromosome 2 has been discovered in a group of German families with a predispositon to Parkinson's disease. Under NINDS and NHGRI sponsorship, scientists are now attempting to find other defective genes that may contribute to PD in other families.

Question. How close are you to discovering the role, if any, that environmental agents play in causing Parkinson's disease?

Answer. There are many theories about the cause(s) of Parkinson's disease. Until recent years, the prevailing theory held that one or more environmental factors caused the disease. Severe Parkinson's-like symptoms were described in people who took an illegal drug contaminated with the chemical MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine) and in people who contracted a particularly severe form of influenza during an epidemic in the early 1900s. Other environmental associations, such as exposure to pesticides, have also been observed but not conclusively proven. In NIH- sponsored studies, scientists have identified the specific genetic abnormalities that cause some forms of Parkinson's in unrelated families. The strong familial inheritance of the chromosome 4 gene is the first evidence that a gene alteration alone may lead to Parkinson's disease in some people. It also opens up exciting new approaches to studying the mechanisms of Parkinson's disease.

In collaboration with the Department of Veterans Affairs and the Parkinson's Institute, the National Institute of Neurological Disorders and Stroke sponsored a study of World War II veteran twins. Recently released conclusions of the study indicate that genetic factors play a major role in Parkinson's disease when the disease begins before the age of 50, but are not significantly important when the disease begins after age 50 years. The significant agents or conditions responsible for caus-

ing Parkinson's disease in persons over 50 are currently unknown. Despite many studies investigating the possible role of environmental factors in causing Parkinson's disease, none have been confirmed.

Question. Do you anticipate that better and longer acting drugs will be developed any time soon?

Answer. At present, most people with Parkinson's disease receive drugs designed to replace or mimic dopamine in the brain. Standard therapy for Parkinson's disease consists primarily of administering the drug levodopa, a substance converted to dopamine by the brain, that often is combined with other agents to enhance its effect. In the early stages of Parkinson's disease, physicians often begin treatment with one or a combination of the less powerful drugs—such as the anticholinergics or amantadine. Bromocriptine, pramipexole, pergolide, and ropinerole are drugs that mimic the role of dopamine in the brain, causing the neurons to react as they would to dopamine. They can be given alone or with levodopa and may be used in the early stages of the disease or started later to lengthen the duration of response to levodopa in patients experiencing wearing off or on-off effects. Selegiline, also known as deprenyl, has become a commonly used drug for Parkinson's disease. Studies supported by the NINDS have shown that the drug delays the need for levodopa therapy by up to a year or more. When selegiline is given with levodopa, it appears to enhance and prolong the response to levodopa and thus may reduce wearing-off fluctuations. Several therapeutic strategies which strengthen the benefit achieved with levodopa are being developed. Talcapone is one such drug that is approved by the Food and Drug Administration for clinical use. A similarly acting compound with fewer side effects, entacapone, is presently under review by the FDA. Many other drugs employing similar mechanisms of action are under development. None of the currently available drugs stops the underlying degeneration associated with Parkinson's. The effects of drug therapy often wear off over time, and they have unpleasant side effects. Researchers are now experimenting with a number of advanced surgical and non-surgical approaches to treating Parkinson's, and hope that these new therapies will help patients who do not benefit from current drugs, perhaps even slowing the course of the disease. The surgeries, pallidotomy, thalamotomy, especially appear to significantly benefit some patients. NINDS is supporting both intramural and extramural studies evaluating what appear to be the extremely beneficial results of the surgical implantation of deep brain stimulators, a procedure that is reversible. The stimulators have been approved for use by the FDA.

STEM CELL RESEARCH

Question. Do you expect a court challenge to your decision to fund this research?

Answer. We do not expect litigation and hope that the openness of the process we will propose in anticipation of funding research utilizing human pluripotent stem cells offers the opportunity to fully engage all those interested in this work.

Question. What is the status of your efforts to develop guidelines and form an administrative oversight group to determine how NIH will fund stem cell research?

Answer. The NIH understands and respects the compelling ethical, legal, and moral issues surrounding pluripotent stem cell research and is sensitive to the need for stringent oversight of this research that goes beyond the traditional rigorous NIH scientific peer review process. In light of these issues, the NIH plans to move forward in a careful way prior to funding any research utilizing pluripotent stem cells.

NIH has convened a working group of the Advisory Committee to the Director (ACD) to develop guidelines that specify what work using these cells can and cannot be supported with DHHS funds and outline restrictions on the derivation of the cells. The Working Group has been asked to propose an oversight mechanism to review research proposals seeking to conduct research utilizing these pluripotent stem cells. The Working Group, composed of scientists, the lay public, ethicists, lawyers and clinicians met on April 8, 1999 in public session. Once the Working Group has finalized draft guidelines for research using human pluripotent stem cells, this draft will be published in the Federal Register for public comment for a period of sixty days. The NIH will not be funding any research using pluripotent stem cells until guidelines are developed and widely disseminated to the research community and an oversight process is in place.

Question. When do you expect to have this process completed?

Answer. We hope the guidelines and oversight process will be operational within the next several months.

Question.

In addition to consulting with Congress while developing these guidelines, who else do you plan to consult?

Answer. The process that we have planned to ensure that any research involving human pluripotent stem cells is appropriately and carefully conducted will take into consideration a broad range of views. The working group of the Advisory Committee to the Director (ACD) to develop guidelines has been asked to consider advice from the National Bioethics Advisory Commission (NBAC), the public, and the Congress.

Question. Do you intend to publish a Request for Applications (RFA) to stimulate additional research using stem cells?

Answer. It is not clear that we will need to publish an RFA to stimulate additional research, at least initially. Our first step has been to convene a Working Group of the Advisory Committee to the Director, to develop guidelines for researchers and to develop an oversight mechanism to review proposals seeking to conduct research utilizing pluripotent stem cells. Draft guidelines will be published in the Federal Register for sixty days for public comment, and applications will be accepted after the guidelines have been finalized and disseminated to the research community. We expect that the research community will be prepared to submit applications through our regular receipt and review process. However, we also intend to advertise to the research community the availability of supplements to ongoing research, for additional studies on pluripotent stem cells. Such supplements would, of course, be subject to our oversight process.

Question. Will the NIH guidelines for stem cell research apply to any activities performed in IVF clinics?

Answer. The NIH guidelines for pluripotent stem cell research will apply to research utilizing human pluripotent stem cells. The guidelines will include restrictions on how the cells used in research are derived. If that work occurs in an IVF clinic, the guidelines will apply.

PARKINSON'S DISEASE

Question. An estimated one million Americans are afflicted with Parkinson's disease. Although there have been major scientific breakthroughs in the past few years, Parkinson's disease continues to exact a costly toll on the United States, both in human and fiscal terms.

In its fiscal year 1999 report, this subcommittee directed NIH to provide a level of funding for Parkinson's-focused on Parkinson's disease where the principle focus of the research is the cause, pathogenesis, and/or potential therapies or treatment of Parkinson's disease, that is consistent with the $100 million Congressional directive in the Morris K. Udall Parkinson's Disease Research Act and the fiscal year 1999 Omnibus Bill. This Subcommittee also directed NIH to report back to Congress (120 days after the passage of the fiscal year 1999 Omnibus Appropriations Act) on progress made toward increasing the level of Parkinson's focused research consistent with the Udall Act.

What steps are you taking to ensure the $100 million will be spent on Parkinson's focused research as directed by the Morris K. Udall Parkinson's Disease Research Act of 1997 and the fiscal year 1999 Omnibus appropriations bill?

Answer. NIH supports a vigorous and expanding program of research in Parkinson's disease, and has taken significant steps to implement the Morris K. Udall Parkinson's Disease Research Act, including its funding goals. New research efforts are augmenting the wide range of basic laboratory studies and clinical trials on Parkinson's disease already being conducted intramurally and at grantee institutions. The issuance of new Requests for Applications and Program Announcements to the research community to encourage several different approaches to the investigation of Parkinson's disease, and the formation of the Parkinson's Disease Coordinating Committee to plan and develop new avenues of research, have already begun to stimulate more new ideas and approaches. Nothing is a higher priority for the lead institute, NINDS, than the identification of causes and movement toward a cure for Parkinson's disease. Estimated total NIH funding for Parkinson's disease research in fiscal year 1998 was $109.7 million, and is estimated to be $127.7 million for fiscal year 1999. This reflects a steady growth in funding over the past five years. As avenues of research continue to be revealed, NIH will assess its Parkinson's disease research portfolio to determine whether additional initiatives are needed.

Question. Where is the report requested by the Subcommittee?

Answer. The National Institute of Neurological Disorders and Stroke, lead NIH Institute for Parkinson's disease, prepared the report in response to the request of the Senate Committee on Appropriations. The final report was forwarded to the Committee on March 15th.

Question. The Morris K. Udall Parkinson's Disease Research Act also directs NIH to sponsor a planning conference on Parkinson's-focused research every two years.

What steps have been taken to organize and design a planning conference on Parkinson's-focused research at NIH?

Answer. Continuing the work and focus of the successful Parkinson's Disease Research Planning Workshop sponsored by NINDS, the National Institute on Aging, the National Institute of Environmental Health Sciences, and the National Institute of Mental Health in 1995, the NINDS and other Institutes concerned with Parkinson's have sponsored additional meetings:

NINDS and the National Human Genome Research sponsored a second workshop on the genetics of Parkinson's disease in December, 1997 at Cold Spring Harbor that has continued to spark research interest. Encouraged by the workshop, additional work is being focused on understanding the products and processes that are affected by the genes involved in familial, and perhaps other, forms of Parkinson's disease.

In April, 1998, NINDS, together with the Office of Rare Diseases, NIH, sponsored a conference to arrive at consensus focusing on multiple system atrophy (MSA). MSA is a neurodegenerative disorder characterized by parkinsonism, cerebellar dysfunction, and autonomic insufficiency. Parkinson's disease is misdiagnosed as MSA in 10–20 percent of cases.

A series of other significant PD research planning workshops on medical and surgical therapies and pathogenesis is planned to begin in the next year.

CLINICAL CENTER: MINORITIES IN CLINICAL RESEARCH

Question. This committee recently held a hearing focused on concerns regarding inclusion of minority populations in clinical research. Does the Clinical Center have patient programs that focus on special problems of minority communities?

Answer. The NIH Clinical Center's Patient Recruitment and Public Liaison Office (PRPL), a multi-cultural and bilingual staff, conducts outreach to minority communities and facilitates patient referrals. Outreach to minorities is accomplished through exhibits at regional and national conferences, presentations to community and professional organizations, and the media.

Print and audio-visual materials used for outreach activities are developed in both English and Spanish. The PRPL operates a phone center with a toll-free number (1–800–411–1222) where prospective patients receive information about research studies.

In January, 1998, the Clinical Center initiated activities to assist with patient recruitment, by targeting women and minorities who are under-represented in the patient population. The PRPL convened a Community Leadership Council, comprised of leaders from a cross-section of the minority community, to act as liaisons to the larger minority community and forge long term relationships.

The Clinical Center continuously looks for opportunities to encourage minority populations to participate in clinical trials. For example, child care is an issue for mothers participating in clinical studies. Recently, the Clinical Center established a pilot drop off service to provide child care during outpatient visits to the Clinical Center. This service will help patients who are unable to secure child care keep clinic appointments.

The Clinical Center has noted an increasing percentage of patients who do not have primary care physicians, particularly patients from disadvantaged backgrounds. Past NIH policy required all patient referrals to come from private physicians. In response to a declining number of patients who have private physicians, the Clinical Center changed its referral policy in 1998 to permit self referrals. This policy change will permit greater access to the Clinical Center to those who have no primary care physician.

Other examples of the Patient Recruitment and Public Liaison Office outreach activities include greater use of conference exhibits. Staff attending conferences distribute materials and answer questions regarding clinical research and the need for patient representation in the development of new treatments in the pursuit of medical breakthroughs. Clinical Center staff network to increase awareness among participants and exhibitors by discussing the Clinical Center—its mission, the patient referral process, and information on clinical services. This past year exhibits were held at the National Hispanic Medical Association National Convention; the National Council of La Raza National Convention; the Nuestra Gente Annual Conference; the Society for the Advancement of Chicanos and Native Americans in Science; the National Association of American Indian Physicians; and, the National Medical Association.

In addition, staff presented workshops and information regarding participation in clinical trials at the Clinical Center to the National Puerto Rican Coalition National Meeting; the National Coalition of Hispanic Health and Human Services Organiza-

tions National Conference; the National Hispanic Medical Association—Board of Directors; and, the National Medical Association.

The Clinical Center has also utilized the media for outreach activities to the public about protocols available for enrollment, including the Hispanic Radio Network; "Hablemos de Salud" in the D.C. Metro area; Pro Salud Magazine; a Public Service Announcement recorded for the Hermansky-Pudlak Syndrome (HPS) Protocol; "La Mexcicana" Chicago radio station; and, "Linea Abierta".

Question. How many patients have been entered into such protocols?

Answer. All patients seen at the NIH Warren G. Magnuson Clinical Center participate in protocols. In fiscal year 1998, 2,869 minority patients were seen.

Question. What has the census been of minority populations in the past year at the Clinical Center?

Answer. The number for minority patients seen at the Warren G. Magnuson Clinical Center in 1998 are provided below. Any patient who was seen for an outpatient visit or who had at least one inpatient day is included.

	Female	Male	Total
American Indian/Alaskan Native	21	22	43
Asian/Pacific Islander	275	253	528
Black (not of Hispanic origin)	966	775	1,741
Hispanic	306	251	557
White (not of Hispanic origin)	6,541	6,981	13,522
Unknown	106	111	217
Total	9,783	9,694	19,477
Total Minority	1,568	1,301	2,869

LYMPHOMA

Question. Lymphoma malignancies strikes upwards of 85,000 Americans each year with a 50-percent mortality rate. Hodgkin's and non-Hodgkin's lymphoma are the second highest cancer rate by incidence. We are currently making strides in the fight against cancer but the rate of incidence of lymphoma is actually increasing. In light of this trend what steps are the NCI taking in conjunction with the Centers for Disease Control and Prevention and the National Institute on Environmental Health Sciences to expand and coordinate efforts on lymphoma?

Answer. The incidence of non-Hodgkin's lymphoma (NHL) has risen each decade since the 1950s. The National Cancer Institute's (NCI) SEER (Surveillance, Epidemiology, and End Results) registry data show an annual percentage increase of 3.2 percent in NHL incidence between 1973 and 1995. Between 1991 and 1995, the rates increased at just over one percent per year. The current incidence rate for NHL is 15.4 per 100,000; the mortality rate is 6.6 per 100,000, with a 5-year survival rates of 51 percent. The American Cancer Society estimates that 64,000 new cases, and 27,000 deaths, from all lymphomas (Hodgkin's Disease and non-Hodgkin's lymphoma) will occur during 1999. The rate of increase of NHL incidence is the second highest among cancer increases, but the incidence rate itself ranks lower than several other cancers. It is nonetheless an important cause of death and disability and its patterns of occurrence warrant the high level of scientific attention devoted to understanding its causes.

NCI is working with the Centers for Disease Control and Prevention (CDC) and the National Institute on Environmental Health Sciences (NIEHS) on several major projects designed to understand whether environmental exposures influence lymphoma risk and, if so, whether these exposures have contributed to the long-term, world-wide rise in lymphoma cases and deaths. For example, the NCI and the CDC collaborated on an important recent study of the role of organochlorines in the risk of lymphoma. The study found no link between lymphoma risk and DDT, a moderate association with lindane, and an unexpected association with polychlorinated bi-phenyls (PCBs).

The critical laboratory assays of compounds present in the blood are conducted by investigators in CDC's specialized laboratory facility. As the NCI research effort grows, NCI and CDC investigators are exploring ways to expand the capabilities of that specialized laboratory to meet our needs for biological measures of past exposures. Similarly, NCI and NIEHS investigators are working together to expand the techniques available for measuring environmental exposures in population studies.

Intramural scientists are conducting very large epidemiologic studies addressing the issue of the environment and lymphoma from a different vantage point, in the

hopes that together they will yield substantially better understanding. In the Multi-Center NHL Case-Control Study NCI investigators, in collaboration with CDC, are examining environmental exposures to pesticides and other compounds by comparing data from personal interviews, blood specimens, household dust, and drinking water in 1200 non-Hodgkin's lymphoma patients and 1200 comparison subjects. A limitation of this case-control approach is that blood measures must be taken after lymphoma has arisen. The Agricultural Health Study (AHS) overcomes the limitation of the case-control approach by studying 90,000 healthy farmers and their family members in Iowa and North Carolina and following them to measure the risks of developing lymphoma. NCI and NIEHS launched the AHS in 1993 as a result of previous NCI research implicating occupational exposures to pesticides in lymphoma; the study will assess the risks of other cancers and diseases. The AIDS-Cancer Cohort recently began following men infected with HIV to examine how environmental exposures interact with the virus to influence which individuals develop lymphoma; this information may be of value beyond the setting of HIV as it may yield more fundamental biologic understanding of the interplay of viruses and chemicals in the development of lymphoma. NCI investigators are conducting or have recently completed investigations of lymphoma trends, of the histologic types of lymphoma that are on the rise, of illnesses including other cancers associated with lymphoma, of occupational groups that may be at increased risk, and of the role of genetic susceptibility.

NCI-supported extramural research covers a similarly wide range of approaches. Examples of lymphoma research in human populations include studies of Hodgkin's disease in children and adults in relation to Epstein-Barr virus and HIV in conjunction with non-infectious environmental factors such as hair coloring, pesticides, nitrates, and solvents; molecular studies of immune changes in HIV-related lymphomas; research measuring genetic changes in tumor cells; population studies of NHL to evaluate the influence of childhood infections, autoimmune disease and chronic infections, UV light exposure, vaccinations, medicinal drugs, and exposure to EBV and other viruses; and studies of tumor genetics to discern the sequence of genetic changes that leads to lymphoma.

LYMPHOMA RESEARCH WORKSHOP

Question. What are the National Cancers Institute's plans to respond to the Subcommittee's request to convene a scientific workshop to examine the current state of lymphoma research and identify opportunities for further study at the NCI?

Answer. The NCI has been instrumental in a number of meetings to help plan for future scientific directions for lymphoma research. NCI researchers were involved in developing the new international classification system for lymphomas, the Revised European-American Lymphoma Classification, as well as a modification of this system by the World Health Organization. Over the past year, the NCI led a series of workshops which resulted in a set of standardized criteria to assess response following treatment of lymphomas (J Clin Oncol, April, 1999). These guidelines will improve our ability to compare results among clinical studies and will help facilitate the identification of more active drugs.

NCI representatives have also led or participated in numerous symposia at national and international meetings to make available to the practicing oncologist information on treatment advance in lymphomas. In addition, NCI representatives regularly participate in lymphoma patient support groups to inform patients and their families about the new advances in lymphoma therapy and to encourage participation in clinical trials.

The NCI has had ongoing discussions with the National Lymphoma Research Foundation and the Cure for Lymphoma Foundation to discuss directions for lymphoma research. A representative of the NCI recently participated in a think tank sponsored by the National Lymphoma Research Foundation, which was conducted to set a national agenda for lymphoma research. The NCI has held two meetings in 1998 with the lymphoma leadership of the Cooperative Oncology Groups to develop and coordinate national strategies for clinical research trials in Hodgkin's Disease and Non-Hodgkin's Lymphoma. The NCI representative will also meet with international lymphoma experts at the International Lymphoma Meetings in June, 1999 to discuss future strategies for lymphoma treatment. Within the next year, the NCI will be initiating a series of State of the Science Meetings, which will attempt to integrate translational research with clinical research and prioritize the most compelling clinical research questions for national studies.

LYMPHOMA RESEARCH AGENDA

Question. Specifically what is the NCI's research agenda on lymphoma?

Answer. The NCI has an outstanding tradition of leadership in basic and clinical research in the lymphomas. The NCI has supported and continues to support many basic and clinical research programs which are attempting to better characterize the immunology and biology of lymphomas, and to increase the potential for cure of these patients. Perhaps more than in any other tumor type, lymphoma research has produced an enormous knowledge base about these tumors, so that we have a better understanding of their biology. In particular, studies in Non-Hodgkin's Lymphoma (NHL) have led to the concept of a defect in programmed cell death, or apoptosis, as critical to the development of lymphomas. An increasing number of genes related to this process have been identified. This knowledge has translated into other tumor types and has provided the opportunity for new targeted approaches such as anti sense and gene therapy.

In the 1960s, NCI investigators developed the first curative chemotherapy program for Hodgkin's disease, and one of the earliest curative regimens for aggressive NHL. More recently, NCI-sponsored clinical trials have defined the standard treatments for early stage and advanced aggressive NHL, and advanced stage Hodgkin's disease. As a result of clinical trials, many of which were sponsored by the NCI, most patients (60 percent–90 percent, depending on the stage of the disease) with Hodgkin's disease can be cured with current therapies, as well as about 40 percent of those patients with aggressive NHL. Unfortunately, there are no curative treatments currently available for patients with indolent NHL, which accounts for 30 percent to 40 percent of NHL patients. Therefore, there are major challenges remaining in the treatment of these diseases. The NCI is involved in sponsoring many investigational protocols directed at improving the outlook for these patients.

The NCI has a long and ongoing history of interactions with pharmaceutical and biotechnology companies which have led to the development of new agents with activity in lymphomas. In recent years, a great deal of attention has been focused on biological approaches to lymphomas. Indeed, the first monoclonal antibody approved by the FDA for the treatment of a human tumor (Rituximab), was developed for NHL through a collaboration between the NCI and the IDEC Pharmaceutical company. Currently, the NCI has agreements with several pharmaceutical companies to develop exciting new agents, including Compound GW506U78, flavopiridol, UCN–01, bryostatin, depsipeptide, and others. Based on exciting preliminary data, the NCI is launching a national protocol for the use of Compound 506U for patients with aggressive lymphomas. The NCI has recently entered into another agreement with the IDEC corporation to study a new antibody against lymphomas that is linked to a radioisotope (radioimmunoconjugate) which, in preliminary trials, has shown extremely exciting activity. Using the Group C and TRC mechanisms, the NCI has facilitated more rapid availability of investigational agents to community physicians and their patients.

The NCI remains committed to improving the outcome of patients with lymphoma through basic and clinical research. Additional research is needed to understand the fundamental questions that are key to continued progress in this field of research. For example, additional studies are needed to better understand the mechanisms by which tumor cells become resistant to our current therapies. A number of important genes have been identified in lymphomas which have been implicated in the cause of lymphoma and in their acquired resistance to treatment. Further studies are necessary to permit the development of specific therapeutic agents directed at those targets.

In summary, the NCI considers lymphomas to be a high priority for basic and clinical research. The research agenda has included developing new and more clinically relevant classifications and guidelines for treatment outcome assessment. Importantly, the NCI supports the research which will enable better understanding of the biology and immunology of lymphomas which will lead to strategies that target specific molecular defects in the tumor. A major emphasis continues to be on testing new chemotherapy drugs and biological agents. Finally, NCI representatives will continue to play a role in educating oncologists in the community and their patients about the most recent advances in the treatment of patients with lymphomas.

QUESTION SUBMITTED BY SENATOR SLADE GORTON

GENE THERAPY CENTERS

Question. It is my understanding that in September 1998 the NIDDK's Advisory Council recommended that, if additional funds were made available, an award should be made to continue the gene therapy research program at the University of Washington. Since that time, your Institute has received a 14 percent increase

in its budget, yet you have not made a commitment to continue this program. Would you explain, why, in spite of significant funding increases for meritorious research, this program was not continued?

Answer. In fiscal year 1999, the NIDDK has funds available for three gene therapy centers. The University of Washington was not competitive for these awards, based on the results of initial peer review. The Center at the University of Washington was given six months of additional funding to carry it through June, 1999. As the year progresses, there will be other centers in the general area of Cystic Fibrosis that will be under review. It is possible that the University of Washington could emerge in a more competitive manner.

QUESTIONS SUBMITTED BY SENATOR JON KYL

STEM CELL RESEARCH

Question. With respect to the January 15, 1999 legal opinion regarding federal funding for research involving human pluripotent stem cells, is it the NIH's position that as long as federal funds are not used for the specific act of destroying a human embryo, they can be used to fund all other parts of a research project that depends on the prior destruction of such an embryo? Was this always the NIH's position?

Answer. NIH has not previously asked the DHHS General Counsel for a legal memorandum explicating Section 511 of the Department's appropriation. The legal memorandum of January 15 finds that the statute precludes federal funding of research in which embryos are destroyed, discarded or knowingly subjected to impermissible risk. The activity not supported by federal funding is the derivation of the stem cells from embryos that are destroyed or subject to more than permissable risk in that process.

Question. You testified before the House Commerce Committee in June of 1997 about prohibited research that was allegedly conducted by Dr. Mark Hughes. In your testimony you described the wrongdoing as involving the diversion of NIH equipment and trainees, which were on loan to Dr. Hughes for single cell biology research at Georgetown University, to prohibited embryo research being conducted by the doctor at Suburban Hospital in Maryland. The NIH apparently severed its ties to the doctor after looking into the matter. Doesn't the NIH's broad interpretation of the funding ban in 1997 conflict with the very narrow interpretation that is reflected in the January 15, 1999 legal opinion?

Answer. The interpretation of the prohibition on federal funding of human embryo research reflected in my referenced testimony of June 19, 1997, does not conflict with the interpretation in the January 15, 1999 legal memorandum of the HHS General Counsel. In my testimony, I stated that Dr. Mark Hughes' pre-implantation genetic diagnostic research, using NIH equipment and trainees, subjected human embryos to risk of injury or death greater than that allowed for research on fetuses in utero under 45 CFR 208(a)(2) and section 498 of the Public Health Service Act, in violation of the human embryo research federal funding restrictions. That situation involved federally funded research on embryos, while the legal memorandum addressed research on human pluripotent stem cells, which are not embryos.

Question. How does the NIH expect stem cells to come to be in federally funded research projects?

Answer. NIH has not begun reviewing any proposals for federally funded research utilizing human pluripotent stem cells and, thus, is unable to predict what those proposals will contain or how they will propose to operate.

Question. In other words, do you anticipate that federal funds will be used to acquire a supply of the cells or to compensate researchers or laboratories for acquiring and providing them? Would such compensation not violate the federal funding ban?

Answer. NIH will receive advice from the National Bioethics Advisory Commission and from a Working Group created to develop, with broad input, guidelines for federal funding of research utilizing human pluripotent stem cells. Those consultations and deliberative processes have not yet been completed, so it is not possible to state what the boundaries of federal funding of such research will be.

Question. Alternatively, if the cells are donated or provided at no cost, how will the NIH assure that federal funds are not used indirectly to help acquire the supply (e.g., as in the Hughes case when NIH-funded equipment was utilized in prohibited research)?

Answer. As with all NIH grants and grantees, and without regard to the means through which any federally funded researchers acquire human pluripotent stem cells, NIH will carefully monitor the activity of researchers receiving NIH funds. As in the case of Dr. Hughes, if there is wrongdoing, it will be promptly sanctioned.

Question. Some research has apparently shown an unexpected degree of success in adapting adult stem cells to become more versatile and to produce a wide variety of other cells. Dr. Ronald McKay, a stem cell expert at the National Institutes of Health, has said that this research points to "alternative strategies" to the use of embryos. Wouldn't it be prudent for the NIH to pursue these ethically acceptable alternatives first?

Answer. The 1999 report in Science showing that stem cells taken from the mouse brain and grown in culture can be returned to a mouse to produce blood cells was another in a series of recent breakthroughs that are changing our view of stem cells. This finding suggests that adult stem cells previously thought to be committed to the development of one line of specialized cells may have more flexibility than previously thought. If this finding holds true for human adult stem cells, there is, indeed, enormous potential for using such adult stem cells as therapies for a number of diseases. It is important to note, however, that breakthroughs in the treatment and diagnosis of disease are, most often, the result of pursuing many varied lines of research that have a common goal.

Question. Might the use of adult stem cells be more promising than some of the proposed embryonic experiments because cells taken from the patient would not be rejected by that person's immune system?

Answer. Cells taken from one's own body would be less likely to produce an immune response and to be rejected than cells from a "foreign" source. However, it is important to understand that human adult stem cells have been isolated only from a few types of tissue and, when they have been identified, they are often present in only minute quantities and are difficult to isolate and purify. In addition, the isolation and growth of sufficient numbers of one's own cells takes time. For some disorders or injuries, banked stem cell-derived tissue from a variety of sources that could be matched to different recipients would be a better alternative. Also, it is important to note that breakthroughs in the treatment and diagnosis of disease are, most often, the result of simultaneously pursuing many lines of research that have a common goal.

NATIONAL MULTIPURPOSE RESEARCH AND TRAINING CENTERS

Question. Arizona is home to one of NIDCD's five National Multipurpose Research and Training Centers. Because of this, the state has become one of the nation's centers for diseases of the nervous system—such as Parkinson's, Alzheimers, and stroke—that effect speech and language. As you know, these diseases afflict a disproportionate number of our senior citizens.

The Arizona National Center was instituted to train clinicians and families throughout Arizona and America on how to treat these diseases. It has become a principal resource in our region to help those afflicted with these diseases and their families through treatment, support groups, and educational programs.

As you know, NIDCD is planning to phase out Arizona's National Center. Could you provide any statement on what the projected impact of the phasing out of this center would have on our state and region?

Answer. The NIDCD cannot say with certainty what the impact on Arizona or your region will be, because NIH awards grants based on peer review of their scientific merit. The decision not to further extend the RTC awards was reached after much deliberation on the part of Institute staff, driven in part by the recommendations of the NIDCD Work Group on Single and Multiple Project Grants (a group of distinguished scientists from the NIDCD constituency) as well as by feedback on their recommendations received from the broader scientific community (http://www.nih.gov/nidcd/notice.htm). We have concluded that: (1) excellence in each of the four activities supported within an RTC is best served by reviewing and supporting each activity separately rather than as a composite; (2) research and research training being conducted by the RTCs can be supported by other grant mechanisms used, or being developed by, the NIDCD; (3) the continuing education activities should be supported with resources provided by sources other than NIDCD; and (4) that the information dissemination activities are important to the mission of the NIDCD, but should be supported through an alternative mechanism. We are currently developing such a mechanism.

Scientists and clinicians in institutions that are able to demonstrate excellence in one or more, but not necessarily all four activities, will be able to compete for support. By expanding the number of individuals able to compete for support to conduct these important activities, we optimize the likelihood of supporting the very best applications NIDCD can receive. Academic and research institutions in Arizona will be eligible to compete for grant support for research, training, and information dis-

semination. The only change is that grant applications for each of the activities will be reviewed and supported individually to ensure excellence in each activity.

QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

CLINICAL RESEARCH

Question. Dr. Varmus, one of your priorities is to "Reinvigorate Clinical Research." I agree that this is a high priority. It seems to me that we need to do this in order to translate basic research into improved human health. Is reinvigorating clinical research a high priority of all of the NIH institutes?

Answer. Yes, reinvigorating clinical research is a high priority of all NIH institutes. The NIH recognizes the importance of translating basic research findings to clinical settings. Each Institute and Center (IC) supports clinical research and clinical trials portfolios that are consistent with its mission. In addition, each IC supports an array of clinical research career development programs, e.g., individual-based (K08) or institution-based (K12) programs. These are ongoing programs that have received renewed emphasis in many institutes.

An additional example of the institutes' support for clinical research is their firm commitment to the new NIH-wide clinical research training and career development initiatives, the Mentored Patient-Oriented Research Career Development Award (K23), the Midcareer Investigator Award in Patient-oriented Research (K24), and the Clinical Research Curriculum Award (K30). These programs have been enthusiastically received by the research community. We have received nearly 200 applications each for the K23 and K24 programs, and over 60 applications for the K30 programs. Depending on the outcome of the reviews, it is anticipated that the NIH will meet its targets of funding approximately 80 K23 awards, 50–80 K24 awards and 20 K30 awards in fiscal year 1999.

Question. And, are all of the institutes spending about the same percentage of their budgets for clinical research?

Answer. While all of the institutes support clinical research, they do not spend the same percentage of their budgets for this area of research. The missions of some institutes (e.g., NIGMS and NHGRI) are simply more basic research oriented.

Question. What percentage of the overall NIH 1999 budget will be devoted to clinical research?

Answer. NIH will spend 31 percent of its budget on Clinical Research in fiscal year 1999.

Question. Will NIH be able to spend the same percentage for clinical research under the fiscal year 2000 budget?

Answer. Yes, NIH will be able to spend the same percentage (31 percent) on Clinical Research in fiscal year 2000.

RESEARCH ON AGING

Question. Dr Varmus, research has extended life expectancy. But that in itself has created new problems. Quality of life problems. I'm thinking about keeping our seniors independent. In your opinion, are we supporting a sufficient amount of research on such disorders as osteoarthritis and concentrating our research investment on mortality?

Answer. Research designed to increase our knowledge of how to maintain mobility and independent function in older persons is a priority for the National Institutes of Health. The National Institute on Aging (NIA) and the National Institute on Arthritis and Musculoskeletal Disease (NIAMS), as well as other institutes, support basic, epidemiological and clinical investigations on diseases which limit functional independence in older persons. Studies designed to treat osteoporosis and osteoarthritis have been and are a focus of the research carried out by NIAMS and NIA. The need for lifestyle changes including diet and exercise, as well as the appropriate use of medication, are important topics which have been investigated by the NIA. One example of this has been a study of walking as a treatment for osteoarthritis of the knee in older persons which resulted in improvement in self-rated pain and disability as well as in objective measures of mobility. The reduction of disability is a critical priority of NIH-supported research. Recently published findings resulting from NIA-supported research indicate that since 1982 there has been a substantial and accelerating decrease in rates of disability among Americans aged 65 and older. Continued research efforts will be targeted at causes of disability such as osteoarthritis and osteoporosis to ensure continued improvement in quality of life for older men and women. These studies may also result in an additional benefit, decreasing mortality rates and increasing longevity.

MULTIPLE MYELOMA RESEARCH FUNDING

Question. How many research project grants over the past 5 years have been awarded which primarily focus on multiple myeloma?

Answer. The NCI conducts a modest program of research in multiple myeloma. It is particularly difficult to provide a precise record of the grants awarded in multiple myeloma over the last five years. This is because recent research in angiogenesis suggests that this field may be extremely relevant to multiple myeloma, but this research is not currently coded in our portfolio for this disease.

In addition, our knowledge of this field is still limited and reporting the numbers of awards which primarily focus on multiple myeloma requires some assumptions to be made which are based on professional judgment rather than quantifiable facts. To answer the question, we have assumed that projects which have one quarter of the effort directed to multiple myeloma should be regarded as primarily focused on multiple myeloma—approximately half of the multiple myeloma portfolio. From this perspective, the number of awards for each of the past five years are with at least 25 percent relevance to multiple myeloma are:

	1994	1995	1996	1997	1998
Number of awards:					
Competing	3	3	7	6	8
Noncompeting	14	12	11	12	14
25 percent or more related	17	15	18	18	22

I would like to caveat these estimates. As with most estimates for a subset of the science supported by the National Cancer Institute, questions about multiple myeloma raise questions of definition and of classifying projects in mutually exclusive or overlapping areas. A different group of scientists might review our portfolio and arrive at a slightly different estimate of funding.

Question. How many have been approved but not funded because of the lack of funds?

Answer. The estimated number of approved competing applications with at least 25 percent relevance to multiple myeloma research are:

	1994	1995	1996	1997	1998
Number of Competing Applications/Awards:					
Approved	10	8	14	14	24
Funded	3	3	7	6	8
Unfunded	7	5	7	8	16

Question. What were the funding levels for the approved grants?

Answer. The funding for grants with 25 percent relevance to multiple myeloma (including new and noncompeting grants) is:

	1994	1995	1996	1997	1998
Number of awards	17	15	18	18	22
Dollars in millions	2.6	3.3	3.9	3.4	5.4

Question. Exclusive of clinical trials, how many grants are expected to be funded for multiple myeloma in fiscal year 2000?

Answer. Assuming a similar level of appropriation, NCI will continue to provide a consistent funding level for multiple myeloma. The total funding for multiple myeloma research in 2000 is estimated to be $12 million. Based on prior year trends, about half of this, or $6 million, will have at least 25 percent of the effort directed to multiple myeloma.

Question. What are the fiscal year 1999 and proposed fiscal year 2000 budgets for basic science research in multiple myeloma?

Answer. The NCI estimates that the multiple myeloma funding in fiscal year 1999 will be $11,700,000 and that the fiscal year 2000 multiple myeloma funding level will be approximately $12,000,000.

Question. What advancements have been made from multiple myeloma research What has been learned from multiple myeloma research at NCI?

Answer. The NCI has sponsored a number of basic laboratory and clinical trials that have advanced our knowledge and treatment of multiple myeloma. Progress in understanding myeloma has been hampered by a lack of a suitable model for the disease. Dr. Epstein and coworkers at the University of Arkansas have developed such a model in an immunodeficient mouse. They were able to demonstrate that myeloma cells from about 80 percent of patients were able to grow in this system. This important observation will provide a framework for studying the biology of the disease and evaluating novel therapies.

The Southwest Oncology Group, one of the NCI-sponsored cancer treatment cooperative groups, completed a clinical trial evaluating the role of steroids and interferon as maintenance therapy. They treated 233 patients with a standard induction regimen (VAD). Those that responded were then randomized to either interferon or the combination of interferon plus steroids. The group that received the combination treatment had twice as long a time to progression and lived almost a year longer than the other group. Subsequent studies are determining if the interferon is actually needed.

Several lines of evidence suggest that angiogenesis may play a role in the development of multiple myeloma. Dr. Barlogie and coworkers at the University of Arkansas conducted a clinical trial using the anti-angiogenesis agent, thalidomide, to treat 89 patients with high risk disease. About a third showed a reduction in tumor-associated protein, with clearing of the bone marrow evidence of the disease in almost half of the assessable patients. Larger clinical trials are now being organized to build on these important observations.

Question. Who is the NCI contact for further questions regarding multiple myeloma?

Answer. The multiple myeloma contact for clinical and research issue at NCI is Dr. Bruce D. Cheson, Phone 301–496–2522.

Question. I am especially concerned about the very high incidence and mortality in African Americans, especially following the IOM's recent report that NCI does not sufficiently fund cancer research focused on minority population. What is being done to address the disparate levels of myeloma incidence and mortality in African Americans?

Answer. The high incidence of multiple myeloma in blacks and their poor outcome with standard therapies has been recognized for a long time. This observation led to a national conference held at the NCI to discuss the epidemiology of multiple myeloma, especially as it related to differences between blacks and whites. Unfortunately, there were no reasons identified to explain these findings, although research into this field is ongoing. The NCI has made a concerted effort to ensure adequate accrual of blacks and other minorities onto its cooperative group cancer treatment trials in multiple myeloma. Group minority accrual is carefully monitored and, if not felt to be adequate, plans are developed to improve on this performance.

NCI BUDGET IN 2004

Question. The cancer community has come forward with a research agenda which calls for the annual NCI budget to increase to $10 billion by 2004. Is this a well reasoned plan and are there adequate research opportunities to absorb this level of growth in the next five years?

Answer. I believe you are referencing the recommendations emanating from the Cancer March on the Mall that occurred several months ago. That call for a $10 billion effort for cancer research in 5 years is most challenging and would represent a major ramping up of our current efforts. If NCI received additional funds above the President's budget request, NCI would apply them in support of these activities: (1) Sustain at full measure the proven research programs that have enabled us to come this far; (2) Seize extraordinary opportunities to further progress made possible by our previous research discoveries and; (3) Create and sustain mechanisms that will enable us to translate rapidly our findings from the laboratory into practical applications that will benefit everyone. Among the initiatives that would be addressed with buildup to a $10 billion investment are:

Basic research and discovery

An enhanced level of support for all types of investigator-initiated research remains a fundamental need. Research in the laboratory, clinic, and community provides the platform on which translational research and clinical testing stand. To ensure that excellent ideas have a chance to be tested, and new investigators are attracted to research on cancer, support for approximately half of the approved applicant pool would be possible.

Clinical trials

NCI is aiming for a five-fold increase over the next five years in the number of people participating in cancer prevention, detection, diagnosis, and treatment trials through the NCI-supported Cooperative Treatment Trials Program. Approximately 300,000 individuals participate in all NCI-sponsored clinical trials; increasing this number five-fold will ensure that over one million patients each year will have access to the latest treatments and preventive, detection, and diagnostic techniques through a clinical trial. NCI is also ready to pilot a newly designed national clinical trials program to test new approaches to the treatment and prevention of cancer. This program will offer more innovative trials to a larger number of participating physicians and patients. Additional funding would move this reconfiguration forward and enable NCI to migrate studies to this new program not only in prostate cancer, but also in breast, genito-urinary, and lung cancers, and leukemia.

Preclinical development

Studying human cancers in mice has made significant contributions to our understanding of the biological mechanisms of cancer. Technology has now advanced to the point that it is possible to develop and validate mouse models of human cancer. Access to these models by the research community is critical to advancing the fight against cancer. Additional investment and the development of an infrastructure to support, manage, and efficiently distribute these powerful new tools is needed. NCI has developed and planned a number of innovative activities in an effort to meet the needs of the cancer field in this area.

Detection

NCI recognizes the need for a coordinated national to accelerate translation of discoveries into early detection technologies. As an example the Early Detection Research Network, has been launched. This multi-center network will provide resources for essential translational research linking basic sciences, clinical sciences, public health, biostatistics, informatics, and computer sciences. The network's goals will be to discover and to coordinate the evaluation of early biological indicators, or biomarkers, of an elevated risk or presence of a cancer. Additional efforts including the identification of environmental agents that damage the DNA with the deign of protective agents is an area for pursuit. Also, a comprehensive public education program regarding screening and risk profiling including the underserved populations would be possible.

Studying emerging trends

For over 25 years, NCI's Surveillance, Epidemiology, and End Results (SEER) database has tracked in impact of cancer on the American people. SEER has allowed us to identify environmental carcinogens and to assess the influence of risk factors associated with behavior and lifestyle while maintaining the highest level of individual confidentiality. Additional resources would enhance the SEER program so that it not only accurately tracks changes in cancer rates, but also contains information necessary for the scientific interpretation of these data and for the planning of additional risk factor research and public health intervention programs.

Diagnosis

NCI expects that tumor diagnosis and classification will be revolutionized in the coming years as emerging knowledge in molecular genetics is applied. Some of this information will be gained through NCI's newly established Tumor Gene Index, which will catalog the genetic characteristics of tumors at each stage of growth. Also new, minimally invasive diagnostic techniques that are emerging from the work of the NCI's Cancer Genome Anatomy Project, Imaging Sciences Working Group, and elsewhere must also be applied and tested in people. To accomplish this aim, the NCI would like to establish a multi-center trial network in diagnostic imaging. To address the need for a new, molecular-based tumor classification system NCI has launched the initiative the Director's Challenge: Toward a Molecular Classification of Tumors. This challenge is to the scientific community to harness the power of contemporary molecular analysis to create a more informative tumor classification system. This "Director's Challenge" is intended to lay the groundwork over a five-year period for changing the system of tumor classification from a visual to a molecular basis.

Cancer prevention

NCI believes it is important to determine the most effective age to begin cancer prevention programs. Priority for new resources would be given to developing innovative, effective interventions for children at early ages, under 10 years of age, when they are most receptive to parental and adult influences. Environmental influences

also have an impact on children. Areas of particular concern and opportunity during early childhood for prevention of cancer include, but are not limited to, tobacco use, sun exposure, and diet and nutrition. Tobacco use research will focus on areas where there are gaps in knowledge, such as adolescent smoking and the use of non-cigarette tobacco products, and will train the next generation of tobacco-use researchers.

Treatment research

Unprecedented opportunities exist to exploit recent advances in biology, chemistry, and technology to accelerate the discovery and testing of new cancer therapies. Over the next five significant effort could be directed to further develop novel approaches. Currently, through a number of new initiatives, NCI is attempting to foster the rapid development of cutting-edge cancer therapies. A major barrier limiting development and testing of new agents in patients is the costly and specialized process involved in drug synthesis, formulation, pharmacology, and toxicology testing necessary to launch initial clinical trials. NCI has established the Rapid Access to Intervention Development (RAID) and Rapid Access to Preventive Intervention Development (RAPID) programs to assist researchers as they navigate the process of moving agents from the laboratory to the clinic. Through RAID and RAPID, investigators compete for access to NCI's development resources. NCI is also expanding its National Cooperative Drug Discovery Groups that link academic and industrial research groups and its Chemistry-Biology Centers that bring together experts in chemical diversity generation and assay development.

Improving quality of life for cancer patients

Among the pursuits of the NCI is to improve the quality of life of cancer patients, including the need for the management of cancer pain as well as the medical needs of the long-term cancer survivors. New therapies for cancer pain improve the lives of cancer patients while new and effective treatments are extending people's lives. Additional biobehavorial research and psychosocial intervention would be pursued. As the U.S. population ages, living with cancer will be a reality for a growing number of Americans. Through quality of life research and activities, NCI is already making it easier for people with cancer to live longer, healthier and fuller lives.

Training and education

We need the resources to train the scientists of tomorrow starting today. We need new kinds of scientists that cross disciplinary boundaries to meet the complex challenge of cancer. NCI has reviewed its training programs to identify how we could best train young investigators coming into the field and continue to develop the skills of scientists already pursuing cancer research. We have developed a strategic plan that is responsive to the needs of students, young investigators, midcareer scientists, and clinical investigators enabling them to stabilize and sustain productive research careers. New training initiatives are aimed at cross-training multidisciplinary scientists, at training physicians in the skills of clinical research, and at attracting increased numbers of minority students and young scientists into all aspects of cancer research.

NEI BUDGET

Question. Why, has the National Eye Institute (NEI) been receiving among the smallest percentage increase of all the NIH Institute and Centers, given the magnitude of eye and vision disorders which will be occurring as the baby-boomers age in the next decade?

Answer. The fiscal year 2000 President's Budget Request includes a proposed increase of 2.4 percent for NEI. This percentage increase is in line with that proposed for the other NIH Institutes and Centers. NEI, through its long-range planning process, has identified a number of high priority areas for vision research that it will pursue to the fullest extent possible within this or any other any level of funding.

Question. When I look at the figures, the NEI's funding as a percentage of the NIH total is on the decline. Can you explain what is behind this trend in light of the pressing issues relevant to macular degeneration, cataracts, and glaucoma in older Americans?

Answer. The fiscal year 2000 President's Budget Request includes a proposed increase of 2.4 percent for NEI. This percentage increase is in line with that proposed for the other NIH Institutes and Centers. It is true that NEI's funding has declined relative to that of the NIH as a whole. However, it should be pointed out that NEI did receive steady increases during the same period. In fiscal year 1999, for example, NEI received an increase of more than $40 million. These funds have been put

to good use in advancing research on the many eye and vision problems which affect older Americans. Other areas of research that have grown faster than NEI, such as the Human Genome Project, will also yield results that will greatly benefit the search for answers to eye and vision diseases.

Question. The NEI is among the largest of the NIH's neuroscience institutes, percentage-wise and in terms of funding. Over the past few years, the Institute has been increasing its neuroscience portfolio to include promising areas such as brain imaging and nerve rescue and regeneration. And yet, over this same period, it does not seem like much of your earmarked neuroscience, sometimes called "Decade of the Brain," monies went to the NEI. Can you explain this allocation pattern?

Answer. The fiscal year 2000 President's Budget Request includes a proposed increase of 2.4 percent for NEI. This percentage increase is in line with that proposed for the other NIH Institutes and Centers. Within the amount proposed for NEI, a significant portion will be devoted to neuroscience research. Among the research areas that will be actively pursued include studies on the guidance of developing neural connections within the visual system, retinal cell and tissue transplantation, nerve rescue and regeneration, brain imaging, and on the prevention of myopia (nearsightedness).

Question. As you know, I am a strong proponent of diabetes research. I was very pleased with the passage of the Balanced Budget Act of 1997, that included a provision for the NIH to receive approximately $30 million per year for each of 5 years, for research on the causes, prevention, and treatment of diabetes. I am puzzled by the small amount of money that has been directed to vision research. As you know, loss of vision is a major, and very devastating, complication of diabetes. Why is it that the NEI received only $2 million of NIH's $30 million.

Answer. In fiscal year 1998 the NEI joined with several other NIH institutes in issuing an RFA (Request for Applications) entitled "Pathogenesis and Therapy of Complications of Diabetes". As a result over 140 applications responded to the RFA and were reviewed for scientific merit. Approximately 40 applications dealt with research on the visual system. Of these, nine applications were funded. In addition, NEI funded supplements to already funded applications for a total expenditure of $2 million. The NEI subsequently funded two additional competing grants from this pool of applications using its appropriated grant funds.

In fiscal year 1999, one new RFA has been issued with relevance to NEI entitled "Pilot Studies for New Therapies for Type 1 Diabetes and Its Complications." It is expected that a number of eye and vision related applications will be submitted in response to this RFA.

AUTOIMMUNE RESEARCH

Question. The NIAID is proposed to receive $30 million of funding for autoimmune diseases. The Conferees, in the fiscal year 1999 Conference Report, wants the NIH Autoimmune Diseases Coordinating Committee to coordinate autoimmunity research on the NIH campus. What are your plans to coordinate this activity? How will the $30 million be distributed to the Institutes and Centers conducting research on autoimmune disease?

Answer. The Autoimmune Diseases Coordinating Committee, a trans-NIH working group, provides coordination and focus for autoimmunity research at NIH. The group worked to develop a framework for autoimmunity research and to generate cross-cutting initiatives that address multiple autoimmune diseases. After consultation with NIAID Director Dr. Anthony Fauci and leaders from relevant NIH Institutes, the plan was approved by the Director, NIH. Support will be provided for a broad spectrum of autoimmunity research projects from basic pathogenesis to clinical trials and selected initiatives focused on specific diseases or extraordinary scientific opportunities. The trans-NIH autoimmunity working group developed a plan that includes 16 research initiatives and the involvement of multiple Institutes, Centers and NIH OD offices. Funding for these initiatives will be allocated based on the applications received in response to each of these initiatives. Applications will be assigned to specific Institutes or Centers for potential funding using established referral guidelines and then evaluated for scientific and technical merit.

MACULAR DEGENERATION

Question. Is it correct that there are vitamins and nutritional supplements that can improve the health of the macula and perhaps prevent macular degeneration?

Answer. This question has not been definitively answered. The National Eye Institute, however, is supporting a large, randomized clinical trial (the Age-Related Eye Diseases Study) which will provide important information as to the protective effects of antioxidant nutrients and zinc. Oxidative damage to the retina is theorized

to increase the risk of age-related macular degeneration. Because antioxidant nutrients and carotenoid pigments concentrated in the macula may offer a protective effect against this oxidative damage, a number of observational, animal, and laboratory studies have been conducted. These studies have provided leads as to which nutrients might be important in protecting the retina against damage, but study results to date have not been conclusive nor has any specific vitamin or nutritional supplement been identified as protective against AMD. Lutein and zeaxanthin are carotenoids that are concentrated in the retina and lens and have been reported in observational studies to decrease the risk of AMD. The NEI has a strong commitment to determine the best way in which to evaluate the effect of lutein on eye diseases and has encouraged preliminary work to determine the appropriate pharmacologic dose of lutein in an elderly population and encouraged work to improve methods to reliably measure macular pigment. These preliminary studies will guide future work in this area.

AGE-RELATED MACULAR DEGENERATION

Question. I read in your fiscal year 2000 Congressional Justification that the NEI is working on identifying which gene mutations may contribute to the development of age-related macular degeneration. Please discuss the research that is being conducted on this topic.

Answer. The NEI continues to devote significant resources to the identification of gene mutations in age-related macular degeneration (AMD). About two years ago NEI-supported investigators reported identification of a gene called ATP-binding transporter gene (ABCR) in Stargardt's disease, a recessive macular dystrophy similar to ARMD but occurring in younger persons. Shortly thereafter, the same team identified mutations in the Stargardt's gene in a limited group of persons with AMD. However, some recent work by other NEI-supported scientists casts some doubt on this association. Work also continues on the identification of the location of other genes such as that for Dominant Radial Macular Drusen, an autosomal dominant macular disease that shares some clinical features with AMD. Investigators have been able to pinpoint the location of this disease gene to a small portion of chromosome 2. As the location on the gene is further refined it will be possible to begin to analyze genes located in this area of the chromosome for mutations. Geneticists at Merck Research Laboratories recently discovered "bestrophin", the gene causing Best's disease. The function of the protein coded by this gene is not yet known. The Best's disease gene had been localized to chromosome 11 by NEI-supported scientists in 1992.

LOW VISION/VISION IMPAIRMENT

Question. What is the NEI doing to assist the individuals (particularly the elderly ones) that are diagnosed with macular degeneration, who have uncorrectable vision and who are in need of special services and devices?

Answer. Through its information office, the NEI currently provides information on a variety of low vision resources including those available from national and state organizations. This fall, the National Eye Health Education Program will launch a new public education program aimed at addressing the needs of people over age 65 with low vision. The low vision program will be instrumental in informing Americans about visual impairment and how the use of visual devices and rehabilitative services can maximizeremaining vision to improve a person's quality of life. A variety of methods will be used to educate the older population including media campaigns, programs for social service and aging networks that service the target population, and public education activities such as exhibits in shopping malls. The NEI is also collaborating with close to 60 national organizations in the NEHEP Partnership to ensure that manpower and resources are available to meet the needs of our aging population.

NEUROSCIENCE

Question. "Biology of Brain Disorders" or neuroscience continues to be one of NIH's "Areas of Emphasis". According to your fiscal year 2000 budget, the NEI is a participant in this initiative. Please discuss some of the neuroscience research that NEI is conducting.

Answer. The NEI supports an extensive portfolio of both clinical and laboratory neuroscience research. Visual neuroscience continues to have a significant impact on the advancement of other fields of neuroscience and our understanding of the biology of brain disorders. Current research on the development and regeneration of the retina and the visual pathways in the brain has provided us with critical insights into the basic molecular and genetic mechanisms guiding the "wiring" of the brain

during development. This research has provided a conceptual basis for understanding a wide range of childhood developmental disorders involving the brain. The accessibility of the visual pathways, such as the optic nerve, has enabled scientists to develop powerful models for studying factors which enhance and inhibit the regeneration of the adult CNS. The application of sophisticated recording and brain imaging technologies to the visual system, has helped scientists understand the complex interactions occurring at the interface between sensory perception and motor action in the brain. This research has provided important insights into many higher brain functions that are critical for cognition such as attention, memory, learning and brain disorders affecting these functions. Vision research will continue to play a significant role in this important arena of inquiry.

DIABETES

Question. You have mentioned to us on several occasions that diabetic eye disease can almost always be prevented with early detection and timely treatment. Unfortunately, the problem lies in the fact that only about one-half of the diabetics (those at great risk) are getting annual dilated eye exams. Is the NEI doing anything to get the word out?

Answer. The NEI, through its National Eye Health Education Program (NEHEP), works with close to 60 public and private organizations in the NEHEP Partnership. Through this Partnership, community programs receive educational materials and technical assistance in designing and conducting programs on diabetic eye disease. For the past five years, the NEI has been working in collaboration with over 40 organizations in the National Eye Health Education Program Partnership to encourage people with diabetes to have an annual dilated eye examination, which enables eye care professionals to detect and treat diabetic eye disease. Building on this national network, organizations have been able to reach out more effectively in their local communities, thus contributing to the success of reaching more people at risk from diabetic eye disease. This year, over 15,000 National Diabetes Month kits were distributed to managed care organizations, physicians offices, and community-based organizations to help them plan local activities. In support of these activities, over 1.6 million NEI brochures on diabetic eye disease brochures were distributed. Over 20 million people were exposed to print media articles and ads on diabetic eye disease.

RETINITIS PIGMENTOSA

Question. Retinitis Pigmentosa is discussed in your fiscal year 2000 CJ. How prevalent is this disease? What part of the population does it affect? Might gene therapy be in the horizon for treating this disease?

Answer. Retinitis Pigmentosa (RP) affects approximately 100,000 people in the United States and 1.5 million people around the world with a prevalence of 1 in 4000. Some patients become blind as early as age 30; the majority are legally blind by age 60. Phase I gene therapy clinical trials should begin within the year, so this effort is still in its initial stages. In animal models with retinal degeneration, photoreceptor cells can be rescued by introducing normal genes. Further, virus-based delivery systems have been used successfully in animal models to inhibit the "cell death" pathway and delay photoreceptor death. NEI-funded investigators are actively searching for biological tools that will form the underpinnings for successful gene therapy in humans.

MYOPIA

Question. Many adults are near-sighted or myopic. Is the NEI conducting any research to prevent or treat this common vision disorder?

Answer. The NEI supports both laboratory and clinical research on myopia. Three large clinical projects of myopia are currently underway. The Collaborative Longitudinal Evaluation of Ethnicity and Refractive Error Study is designed to document normal patterns of ocular growth and to develop a profile of risk and predictive factors for myopia in Caucasian, African-American, Hispanic and Asian children. An estimated 3,000 children will be enrolled and followed longitudinally. The Myopia Progression Study is a clinical trial designed to determine whether bifocals reduce the progression of myopia. Children with myopia will be randomly assigned to wear single vision lenses or bifocals. Follow-up eye examinations are planned for a minimum of 3 years. The Correction of Myopia Evaluation Trial is a multi-center clinical trial designed to determine whether progressive addition lenses reduce the progression of myopia. An estimated 450 children with mild levels of myopia will be enrolled and will be randomly assigned to wear single vision lenses or progressive addition lenses. Follow-up eye examinations are planned for at least 3 years.

GLAUCOMA

Question. Is it correct that NEI-supported research has found that certain glaucoma treatments work better on certain minority populations? What are the two treatments in question?

Answer. The Advanced Glaucoma Intervention Study (AGIS) is a multi-center, randomized clinical trial designed to determine the long-range outcomes of two alternative intervention sequences among patients with primary open-angle glaucoma in whom medical therapy had failed. The two treatment sequences under study are either trabeculectomy followed by argon laser trabeculoplasty (ALT) after the initial trabeculectomy failed followed by another trabeculectomy after the ALT failed (sequence TAT) or ALT followed by trabeculectomy after the ALT failed and another trabeculectomy after the initial trabeculectomy failed (sequence ATT). Study findings, reported in 1998, indicate that, at seven years after initial therapy, African Americans may benefit most from the sequence beginning with ALT whereas whites may benefit most from the sequence beginning with trabeculectomy.

CLINICAL RESEARCH

Question. Dr. Battey, is reinvigorating clinical research a high priority of your institute?

Answer. Yes, NIDCD places a high priority on reinvigorating clinical research. Given the remarkable progress that has been made in understanding the basis for communication disorders such as hereditary hearing impairment, there is an unprecedented opportunity to begin to apply this new knowledge to develop more specific and timely diagnostic capabilities, as well as more precise intervention strategies. Developing these new diagnostic capabilities, as well as determining the optimal intervention strategy for each group of individuals with a particular communication disorder, will be important goals for NIDCD clinical research in the near future.

Question. What percentage of your budget will be spent on clinical research in fiscal 1999 and fiscal 2000?

Answer. The NIDCD obligated approximately 45 percent toward clinical research and research training in fiscal year 1998. We would expect to support a similar amount in fiscal year 1999 and fiscal year 2000.

Question. Are you supporting two Clinical Trial Cooperative Group that appeared in this institute's previous budgets? (If nowhy not? It appears that this is one mechanism for translating basic research into improved health.)

Answer. The NIDCD is currently supporting the Clinical Trial Cooperative Groups. In fiscal year 1999, NIDCD will provide $2.4 million to support their clinical research activities.

Question. Do you have plans to expand clinical research in the near future?

Answer. Yes, NIDCD plans to expand its clinical research efforts in a number of exciting new directions. Let me provide two important examples where NIDCD-supported research has lead to new opportunities for clinical research:

(1) There has been a remarkable wealth of new knowledge gained about the causes of some communication disorders, in particular hereditary hearing impairment. Within the last two years, several genes, where mutations are a common cause of nonsyndromic hereditary hearing impairment, have been identified. Mutations in one of these genes have been shown to be the cause of hereditary hearing impairment in up to one half of all children in some population groups. NIDCD is poised to take advantage of this important new information, and convened a Working Group in December, 1998 to seek advice regarding the best way to begin to use this new information in follow-up clinical studies. Their recommendations have been widely disseminated to the relevant clinical communities, and will form the basis for grant applications supporting research to ascertain the best ways to integrate the new genetic diagnostic capabilities into the clinical evaluation of a child with hearing impairment;

(2) Recent research studies supported by NIDCD have shown that children with hearing impairment who are identified and receive intervention within the first six months of life develop better language skills than children whose hearing impairment is identified at a later time. In the near future approximately 19 states will implement programs to screen all neonates for hearing impairment before discharge from the hospital. As this effort expands, the need to define and validate optimal intervention strategies for infants with all degrees of hearing impairment is increasingly clear. The need for clinical studies to accomplish this goal was emphasized in the deliberations of a workshop sponsored by NIDCD to get advice from the research community on the subject of intervention strategies for children with hearing impairment identified in the newborn period. Approximately 10–20 percent of the

infants that will be identified as a result of neonatal hearing screening have profound hearing impairment, while the other 80–90 percent have lesser degrees of hearing impairment, defining multiple populations of infants for whom optimal intervention strategies do not exist, and which remain to be developed and validated through clinical research. In October, 1998, NIDCD solicited research grant applications to develop and validate these needed intervention strategies. I am pleased to report that we are already receiving grant applications in response to this year-long solicitation.

In addition, the NIDCD encourages and supports highly meritorious investigator-initiated clinical research. Looking beyond the next few years, a key component of expanding clinical research is developing the investigators who are rigorously trained to design and conduct these important clinical studies. NIDCD has begun several new programs to help develop this cadre of new investigators. Following the lead of the NIH Director, Harold Varmus, NIDCD launched a new Mentored Patient-Oriented Research Career Development Award, which provides five years of support for young investigators to develop their skills in designing and conducting clinical studies and trials. In addition, NIDCD is supporting the new Mid-Career Investigator in Patient-Oriented Research Award, which provides salary support for mid-career clinical investigators to serve as mentors for their junior colleagues, as well as support for mid-career individuals to design and conduct clinical studies. Finally, NIDCD has created an Otolaryngology Fellow Research Training Program within its Division of Intramural Research. These fellowships provide competitive salary support for otolaryngologists to get 2–5 years of research training in one of NIDCD's outstanding intramural laboratories, with at least 75 percent of their time protected for research training.

Question. For the record, please provide a list of the clinical research you will support in 1999, and also those clinical research projects you intend to support with your fiscal 2000 budget.

Answer. A listing of fiscal year 1998 clinical research projects will be sent under separate cover, as it is too voluminous to print in this document. It is not possible at this time of the year to have a complete picture of all clinical research projects that will be funded in fiscal year 1999. There is still one more Council round (May) for which review decisions have not been made for the grant applications coming before that Council. And of course, the same is true for fiscal year 2000 we do not know what grant applications will successfully compete for support.

NATIONAL MULTIPURPOSE RESEARCH AND TRAINING CENTERS

Question. Dr. Battey, I recently wrote to you, expressing my concern with the decision to phase-out the National Multipurpose Research and Training Centers (RTCs). These Centers not only conduct high quality research, but they also serve as training centers for medical professionals, as well as provide critical information to the general public. If you phase out these Centers, how will NIDCD ensure that the important services these Centers provide will continue to help deaf citizens, their families, and the medical professionals who care for them? I am particularly concerned about the training, continuing education and information dissemination components of their mission.

Answer. The decision not to further extend the RTC awards beyond their expiration in August 2000 or August 2001 was reached after much deliberation on the part of Institute staff, driven in part by the recommendations of the NIDCD Work Group on Single and Multiple Project Grants (a group of distinguished scientists from the NIDCD constituency) as well as by feedback on their recommendations received from the broader scientific community. NIDCD remains committed to supporting research training and information dissemination. We have concluded that: (1) excellence in each of the four activities supported within an RTC is best served by reviewing and supporting each activity separately rather than as a composite; (2) research and research training being conducted by the RTCs can be supported by other grant mechanisms used, or being developed by, the NIDCD; (3) the continuing education activities should be supported with resources provided by sources other than NIDCD; and (4) that the information dissemination activities are important to the mission of the NIDCD, but should be supported through an alternative mechanism. We are currently developing such a mechanism.

Scientists and clinicians in institutions that are able to demonstrate excellence in one or more, but not necessarily all four activities, will be able to compete for support. By expanding the number of individuals able to compete for support to conduct these important activities, we optimize the likelihood of supporting the very best applications NIDCD can receive.

EXTRAMURAL CONSTRUCTION

Question. The need for upgraded, state-of-the-art facilities to conduct biomedical research is critical. Why does the NIH request include only $30 million for extramural construction?

Answer. The request of $30 million for extramural research facilities construction within NCRR is for the same level as was appropriated in fiscal year 1999, and underscores the NIH commitment to support extramural facilities construction. Competitive construction awards provide a "Good Housekeeping stamp of approval" for institutions which can successfully leverage the NIH award several fold with funds provided by private sector donors. Within a 2.1 percent increase in the NIH budget in fiscal year 2000, emphasis was placed on the support of investigator initiated research to the extent possible.

Question. Can the research facilities at universities and academic health centers accommodate cutting edge health-related research?

Answer. The latest National Science Foundation report on extramural research facilities, submitted to several Congressional Committees in March of this year, indicates that approximately 65 percent of institutions responding to the survey reported inadequate space for research. "Inadequate research space" means that either the space cannot accommodate sophisticated research, or the space does not exist. In addition, this survey found that almost one quarter of the research space available was identified as needing major renovation or replacement.

Question. Can universities and other institutions readily identify funds for upgrading their research facilities? What is the projected need?

Answer. To meet their current research commitment, the institutions performing research in the medical and biological sciences reported that they need an additional 18 million square feet of research space, or 32 percent more than they currently have. These data come from the National Science Foundation survey of universities and are in response to a question that asked research institutions to identify optimal facility space without any regard to cost. NIH provides approximately $2.9 billion annually to these institutions through indirect cost payments. A small portion of this supports facility maintenance, repair, and replacement.

Question. How can the NIH reasonably double its budget without a substantial increase in the funding for extramural construction?

Answer. Construction or renovation of extramural research facilities is essential if the NIH budget is to be doubled in the near future. Without appropriate research space, institutions will be unable to perform a greatly increased level of sophisticated research. The source of funding for this construction and renovation might be institutional funds, loans, state or Federal funding.

Question. Can you tell us how much of an institution's indirect costs are used for construction?

Answer. At the request of NCRR staff, the National Science Foundation undertook a funding analysis of the largest 100 research-performing institutions in the "1998 NSF survey of Scientific and Engineering Facilities at Colleges and Universities." The analysis compared the amount of federal facilities and administration reimbursement each institution received in 1997 with the amount of institutional funds the institution reported allocating to research facilities capital projects (new construction and repair/renovation). The analysis revealed that the average institutional cost for capital projects was $5.3 million and the average institutional Depreciation and Use allowance was $1.8 million. In short, the institutions were reimbursed about one-third of the cost of capital projects through indirect costs.

Question. Is the setaside for the Centers of Emerging Excellence the best way to ensure that the neediest institutions receive construction funds?

Answer. The peer review process ensures that all factors are taken into account in determining the most meritorious applications, assessing need, quality of research, plans for the proposed facility, and potential to expand capacity for research.

Question. Why should there be a different matching requirement for construction grants at the Regional Primate Research Centers?

Answer. The Regional Primate Research Centers (RPRCs) are national resources, much like the national laboratories supported by other federal agencies. The RPRCs serve as national resources and accommodate investigator needs across the United States. Consequently, there is no significant incentive for the host university to provide matching funds for state-of-the-art research laboratories to host investigators from other academic institutions.

SHARED INSTRUMENTATION

Question. Is NIH doing anything to address the need for very expensive equipment, for example for high field NMRs, MRIs, (in the multimillion dollar range) to conduct state-of-the-art research?

Answer. In fiscal year 1999, the National Center for Research Resources raised the ceiling for research equipment to $500,000 for off-the-shelf research equipment requested through the Shared Instrumentation program. Nearly half the applications to this program in 1999 requested research equipment for which the cost exceeded the ceiling of the program. Separately, the NCRR and the National Science Foundation established a program four years ago through a Memorandum of Understanding to attempt to accommodate applications for high end, expensive laboratory equipment. The combined program would provide up to $500,000 from each agency. The number of applications has increased substantially, underscoring the need for high end equipment. Unfortunately, the combined effort of the NCRR and NSF cannot meet current needs in this area.

Question. Won't the relatively low level of funds available for shared instrumentation be a limiting factor if NIH should double its budget in the next few years? How much research equipment does NIH provide through grants and is it enough in your professional judgement?

Answer. Funding for shared instrumentation is one of the NIH's important areas of emphasis, and has received substantial support in fiscal year 1999 and the fiscal year 2000 request. If the NIH budget is to double in the next few years, and the research conducted is to be state of the art, more instrumentation will be required. NIH spends only about one percent of research grant funds on instrumentation.

SCIENCE EDUCATION

Question. What programs does the NIH support to address the issues of attracting more young people, particularly young minority students, into biomedical research?

Answer. The NIH supports a variety of programs designed to attract young people into biomedical research. The NCRR supports a Science Education program which develops curricula to make science more interesting to young students and the general public; many of the early projects are now being disseminated around the country. A significant number of the student participants belong to minority groups. Many of the Institutes at NIH have programs of outreach to local schools in the area, bringing in students to perform hands-on research after school and in the summers. Many of these students belong to minority groups.

SYNCHROTRONS

Question. What is the NIH doing to address the need to increase access to synchrotron facilities for macromolecular crystallographic studies?

Answer. The NIH and the Department of Energy are currently engaged in discussions of how to address the need to increase access to synchrotrons for biomedical researchers. In addition, the NCRR is funding more service personnel at synchrotron beamline sites to assist naive users and further increase throughput. Efforts are also focusing on development of more sophisticated detectors and computational algorithms to facilitate data analysis.

FLEXIBLE INSTITUTIONAL SUPPORT FOR RESEARCH

Question. I have been hearing from various groups involved with biomedical research that there is a grave need for flexible funds that can be used by an institution for locally identified needs, such as bridge funding, pilot research or shared resources. Such needs used to be met through the Biomedical Research Support Grant program, which was discontinued in the early 1990's. Why has NIH not reestablished this program, particularly with the growth in the NIH budget?

Answer. The NIH recognizes the benefit of flexible funding, such as that which was formerly provided by the Biomedical Research Support Grants, for research institutions to utilize for locally identified needs, such as pilot studies, bridge support, and shared resources. Several mechanisms have been developed that address some of the needs formerly met by the BRSG program. Several years ago, the NIH initiated the Shannon Grant Award program which provides funds to those applicants just below the payline for new research project grants. This program provides support for pilot studies to strengthen subsequent grant applications. In addition, Institutes and Centers have administrative authority to provide bridge funding for those investigators with grant renewal applications which just missed the payline. This approach allows them to strengthen their amended applications. With such mecha-

nisms as these already in place, the need for a BRSG program is considerably lessened.

GENERAL CLINICAL RESEARCH CENTERS

Question. Is there any way that the GCRCs can play a role in expediting the development of new drugs for the so-called "orphan diseases?"

Answer. The General Clinical Research Centers (GCRCs) currently study many orphan diseases, including the testing of new therapeutics for rare disorders. Approximately 20 percent of GCRC research protocols focus on orphan diseases.

Question. What role can the GCRC play in facilitating drug development, especially for the biotechnology industry where so much of the promising innovation is now occurring?

Answer. Approximately one-quarter of the GCRC-based 6,000 research protocols are for clinical trials. A significant fraction of the agents included for testing are from the biotechnology industry. About 10 percent of GCRC outpatient visits are specifically targeted for industry clinical trials.

NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE

Question. How is the new Center for Complementary and Alternative Medicine (NCCAM) being organized to ensure that the statutory requirements are being met?

Answer. An organization plan was approved by the Secretary, DHHS on February 1, 1999. The NCCAM is organized into: (1) Office of the Director; (2) Office of Administrative Operations; (3) Office of Legislation, Policy and Analysis; (4) Office of Communications and Public Liaison and (5) Division of Extramural Research Training and Review. Collectively this plan has provisions for:

(a) The study of alternative treatment modalities for the purpose of integration into the nation's health care delivery system;

(b) the engagement of scientists with appropriate research expertise in CAM for review of grant applications;

(c) the coordination with other NIH Institutes and Centers as well as other federal agencies to ensure appropriate scientific input and management of grant, contract and cooperative agreement awards for research;

(d) the evaluation of all major CAM systems, disciplines and modalities for which national or state accreditation is available;

(e) the conduct and support of outcomes research, investigations, epidemiological studies, health services research, basic science research and clinical trials;

(f) the formation of a trans-NIH Coordinating Committee composed of responsible and responsive liaisons from each Institute and Center to facilitate appropriate coordination and scientific input;

(g) the establishment of a bibliographic database for CAM scientific citations worldwide for use by researchers;

(h) the establishment of a national clearinghouse for public dissemination of CAM related information to patients, professionals, industry and the general public,

(i) the establishment and support of multi-purpose research centers dedicated to CAM as it relates to a variety of disease conditions.

A national search is underway for a new Director. It is anticipated that a highly qualified candidate will be submitted shortly to the Secretary for her final approval.

A charter has been written for the new National Advisory Council for Complementary and Alternative Medicine (NACCAM). A slate of nominations for membership, including ad hoc members, has been submitted to the Secretary for approval. The NACCAM will have membership in which half will include practitioners licensed in one or more of the major CAM systems and three individuals representing the interests of consumers of CAM. The NACCAM will provide the second level review for funding of all applications that have received prior technical review.

Question. What are you doing to ensure that the Center will focus on clinical trials?

Answer. Clinical trials are critical to building the evidence base for CAM usage. The recruitment for a Director places great emphasis on skills and experience in the planning and conduct of clinical trials. Two advisory committees to the Director, NCCAM should have clinical trial expertise as well. The National Advisory Council for Complementary and Alternative Medicine and the Cancer Advisory Panel for Complementary and Alternative Medicine will include individuals with clinical trials backgrounds. The development of a portfolio of clinical trials is making progress. Several large clinical trials of CAM approaches are being supported or have been announced. These include: proposals in response to a Request for Proposals seeking a clinical trial to test glucosamine either alone or along with chondroitin sulfate for the management of osteoarthritis were recently reviewed; it

is expected that the award will be made this fiscal year. A Request for Applications for a trial to evaluate the efficacy of *Ginkgo biloba* in the prevention of both vascular and Alzheimer dementia was recently released. It is anticipated that the award for this multi-site trial will be made in September 1999. Pilot and smaller clinical trials are being encouraged through program announcements and in the NCCAM Center's program. A Program Announcement for Clinical Trial Pilot Grants in Chiropractic and Osteopathy was released in October 1998 and will be active for three years. This effort will facilitate the collection of data needed for large scale randomized controlled trials on manipulation for clinical conditions other than low back pain. Four applications in response to this RFA were submitted on February 1, 1999. In collaboration with NHLBI, NCCAM issued an RFA for Centers in ischemic heart disease to investigate nutritional supplements and CAM pharmacological agents in the treatment of congestive heart failure and coronary heart disease. These applications are currently under review. Additional clinical trials are in early planning stages for fiscal year 2000. These include *Saw palmetto* for the treatment of benign prostatic hyperplasia; garlic for the prevention of cardiovascular disease; melatonin for the treatment of insomnia; milk thistle (*silybum marianum*) for the treatment of hepatic diseases; and the effects of phytoestrogens on the prevention of cardiovascular disease and the risk of cancer in postmenopausal women.

To facilitate development and efficient conduct of CAM clinical trials in cancer, the NCCAM is collaborating with the National Cancer Institute (NCI) to develop an advisory committee, the Cancer Advisory Panel for Complementary and Alternative Medicine (CAPCAM). The CAPCAM will be chartered and will advise the Advisory Council of the NCCAM on promising CAM interventions that might be tested in clinical trials. The NCCAM, through the NCI has initiated two trials in cancer treatment. One is to determine the efficacy of shark cartilage for specific types of tumors and the other is on the use of a strict nutritional intervention for pancreatic cancer. Additional trials will be planned for other CAM interventions for cancer. The CAPCAM will be meeting regularly to advise the NCCAM on further promising treatments.

Question. How many staff are already on board? At what level? Who is hiring them? Are you providing any training to them in complementary and alternative medicine (CAM)? Will you be providing training to the Institute liaisons in CAM?

Answer. At the present time there are 13 staff permanently assigned to NCCAM, at levels ranging from GS–06 for support staff to GS–15. To assist with program development during recruitment of permanent staff, five experienced NIH staff will join NCCAM on details. Six additional permanent staff, including the Director will be hired over the next several months, following established NIH personnel procedures. They will be selected on the basis of their demonstrated scientific and administrative expertise and experience. It is anticipated that many of these new staff will already have either CAM research experience or a working knowledge of CAM. They will participate in CAM training for all staff and Institute liaisons. The Institute liaisons to NCCAM have been selected for each Institute based on their knowledge and interest in CAM and their management positions within their Institutes and Centers.

A series of CAM seminars are planned in which established investigators knowledgeable in CAM will be invited to speak. These seminars will be held regularly and all NIH staff will be notified. A CAM cancer interest group, comprising of both intramural and extramural scientists from across the NIH has already met. These formal seminars and informal meetings of interest groups not only provide training for staff, but provide other NIH scientists with information about CAM.

Question. Will there be an intramural research program with a scientific director, labs, and staff? If not, why not?

Answer. The scope of research activities conducted or supported by the new Center will include both intramural and extramural research. Intramural research in CAM will be implemented in close coordination with the NIH Office of Intramural Research, and the intramural programs of the NIH research institutes. The fellowship applicants and their projects have been reviewed by the NIH Intramural program. Currently, the Center supports three postdoctoral fellows and their research projects in intramural laboratories of three Institutes at the NIH. Support is provided for the fellows, their research projects and ancillary supplies and equipment plus travel to a scientific meeting. Topics of these three projects are:

(1) "Use of Transcranial Magnetic Stimulation to Facilitate Learning in Normal Volunteers and Patients with Neurological Disorders," in collaboration with the National Institute of Neurological Disorders and Stroke.

(2) "Mechanisms of Acupuncture and Placebo Analgesia," in collaboration with the National Institute on Deafness and Other Communication Disorders.

(3) "Chemokine Inhibitors Found in Folk Remedies from the Americas," in collaboration with the National Cancer Institute.

A fourth intramural project for which the NCCAM provides full funding is for a senior clinical research fellow. Her topic is "Acupuncture and Functional MRI in the Treatment of Alcoholism."

Currently, the Acting Director, NCCAM is overseeing the intramural program. The new Director of NCCAM will be responsible for further development of the intramural program.

Question. Will you have a field investigations program? If yes, what will it look like? If not, why not?

Answer. The Office of Alternative Medicine has conducted field investigations of practice experiences with CAM, but recognized that the Centers for Disease Control and Prevention (CDC) has a wealth of field investigation experience and expertise in their Epidemiology Intelligence Service. Therefore, NCCAM has developed a collaboration with the CDC, to develop a program for investigating the practice outcomes of selected CAM practices. This is supported by an interagency agreement with CDC as it was in fiscal year 1998. Currently two different CAM practices have been visited. It is expected that additional practices will be visited this fiscal year. Practices for these field investigations are identified by an NCCAM practice screening and assessment approach that has been used for several years. In this program, NCCAM staff will visit practices to evaluate their current data for research potential and to assess the ability and willingness of these CAM practices to engage in field investigations and outcomes data collection. To date, 37 practices have been assessed for these factors, for possible future full field investigations.

QUESTIONS SUBMITTED BY SENATOR DANIEL K. INOUYE

WASTE TREATMENT MANAGEMENT BY NATIVE HAWAIIANS

Question. What progress has been made in the study of waste treatment management to address the unique environmental, public health and cultural issues of native Hawaiians?

Answer. In April 1998, the NIEHS Director, Dr. Kenneth Olden, and a staff member attended the Pacific Basin Conference on Hazardous Waste held in Honolulu, Hawaii. This is a conference that is sponsored by the East-West Center of Honolulu, and is held in a different Pacific Rim country every 18 months. The NIEHS has been an active supporter of this East-West Center's activities and their conference on hazardous waste for the last eight years. The primary goal of these interactions has been to seek opportunities to accelerate research on hazardous waste management and to apply research results and new technologies to the actual hazardous waste problems in Hawaii and Pacific Basin countries. While the East-West Center has a strong focus on pollution prevention, NIEHS has encouraged the inclusion of environmental health and cultural issues in the conferences and other activities.

They also met with principals from the Bishop Museum's Education Department and Strategies Hawaii to discuss the use of the traditional cultural waste treatment practices through the "living machine" processes and to identify opportunities for partnership between NIEHS and organizations in Hawaii addressing environmental health issues. NIEHS staff identified three possible opportunities for partnership: (1) the NIEHS K–12 program; (2) the outreach component of the NIEHS Centers; and (3) the outreach component of the NIEHS/EPA Superfund Basic Research Program. As a result of this meeting, staff have maintained ongoing conversations with Strategies Hawaii regarding the "living machine" process and are providing guidance in applying for an upcoming grant opportunity through the NIEHS K–12 program. Based on discussions with the State of Hawaii Department of Health (DOH), the NIEHS Center at the University of Southern California is now collaborating with the DOH to train individuals in exposure assessment. Also, discussions with the University of Hawaii suggest that the University is considering applying for a NIEHS/EPA Superfund Basic Research Program grant. Incorporated in this application would be an outreach and education component for addressing the cultural components of the treatment of waste.

Subsequent to the April meeting, NIEHS staff have identified another possible mechanism for support of waste treatment management by native Hawaiians—the Small Business Innovative Research program. Staff have recently been in contact with Strategies Hawaii regarding the opportunities that are available in this program.

Equally as important, as a result of this meeting NIEHS now has established contacts within the Bishop Museum, the State DOH and the University of Hawaii and

consequently is better positioned to provide guidance for current and future opportunities.

COLLABORATION ON TELEHEALTH RESEARCH

Question. In the fiscal year 1999 appropriations, it was suggested that NINR collaborate with Tripler Army Medical Center on the application of telehealth technologies to nursing practice. In the President's Budget proposal, there is no mention of telehealth research. What are NINR's plans for telehealth research and collaboration with Tripler Army Medical Center and the HRSA's Office for the Advancement of Telehealth? What funding is being allocated for this research?

Answer. Telehealth technology permits nurses and other care providers to establish feedback systems between themselves and patients while preserving the traditional nursing focus on patients in their own environments. As described in NINR's report to the Committee last year on telehealth (requested in Senate Report 105–58), telehealth is especially appropriate for underserved rural settings, such as those in rural areas of Hawaii.

NINR funding of telehealth research, an estimated $1,410,000 in fiscal year 1999, is accomplished once scientifically meritorious applications are received. At present, NINR-supported telehealth research falls primarily into four categories: (1) telephone intervention, in which the telephone call is used to deliver the nursing intervention, such as psychosocial support and patient education information; (2) home monitoring devices used to transmit data electronically to practitioners at a distance; (3) improved and expanded telehealth technology and resources; and (4) computer-based instructional programs.

In response to the Committee's interest in increased nursing research using telehealth interventions and their application to underserved populations, we are exploring a partnership with Tripler Army Medical Center in Hawaii to examine issues of relevance to rural Hawaiian groups. One promising approach is to identify issues important to the health of the Hawaiian population and integrate telehealth nursing research interventions to existing telehealth studies administered by the medical center.

NINR staff are also involved in discussions of ways to interface with services and opportunities offered by the Office for the Advancement of Telehealth at the Health Resources and Services Administration. A fruitful collaboration between agencies would enable a better coordination of our respective efforts to encourage research in telehealth.

QUESTIONS SUBMITTED BY SENATOR HERB KOHL

EPILEPSY

Question. I'd like to direct this question to Dr. Fischbach. Last year, we discussed the need for more funding for epilepsy research. In particular, we focused on the need for research on intractable or uncontrolled epilepsy. I have met with families who have children suffering from this severe disorder, and they need hope now. With the $124 million increase that the National Institutes of Neurological Disorders and Stroke (NINDS) will have this year, as well as the directive report language included in both the Senate and Omnibus Appropriations reports, I think it is clear that Congress intends for epilepsy research to be a priority. What specific plans does the NINDS have to fund more epilepsy research projects this year? Are there already promising areas of research that should be funded immediately?

Answer. NINDS expects to spend approximately $70.7 million in epilepsy research in fiscal year 1999, an increase of $6.9 million over fiscal year 1998. The Institute's epilepsy research portfolio is one of its largest, representing a full spectrum of research from the pathogenesis of the many forms of epilepsy to new medical and surgical approaches to treatment.

We have just held a workshop on the genetics of epilepsy that identified several promising directions for future research, and we will be following up with new initiatives. Recent findings on seizure disorders associated with heterotopias, or abnormal development of areas of the brain, have been made possible through improved imaging and will be pursued further. We plan to conduct trials relating to infantile spasms and trials of drugs in children. It is now clear that most intractable epilepsy involves the concerted action of many genes. This issue can only be approached by collecting large populations of affected families and studying them through consortia and other collaborative arrangements.

Question. What specific plans does the NINDS have to solicit more interest and grant applications to research uncontrolled or intractable epilepsy?

Answer. Intractable epilepsy is a major focus of research interest. All patients with epilepsy will benefit from improved treatments or cures, but the driving force behind our efforts to improve medical and surgical treatments is the need to help persons with epilepsy for whom current treatments are not effective. We are about to fund two major planning grantsone is for a study of intractable seizures in children and the other is for a large multi-center trial to assess the benefits of early surgery for intractable seizures. We are seeking the participation of the small business research community through solicitations encouraging development of better animal models for studying epilepsy and are also working with the American Epilepsy Society and the Epilepsy Foundation of America to encourage new investigators to enter the field.

Better understanding of the various forms of epilepsy has contributed to the development of a greater variety of drugs with different mechanisms of action, and improvements in imaging and surgical techniques are leading to better surgical treatments. We want to continue these efforts even more aggressively, with a special focus on evaluating drugs for treatment of children. We are committed to working with industry to develop new treatments and evaluate existing drugs and combinations of drugs in various groups, especially children. A major conference on finding a cure for epilepsy, to be held next year, will focus special attention on the problem of intractable epilepsy.

Question. I realize that many epilepsy research projects in the past have focused on finding new treatments. But what these families really need is a cure. How does NINDS intend to meet this need?

Answer. We share this goal, and we are pleased to announce that NINDS will serve as primary sponsor for a White House-initiated "Conference on a Cure for Epilepsy" to be held March 30–31, 2000. Initially suggested by First Lady Hillary Rodham Clinton, the conference will cover a broad range of science and therapeutic opportunities, and will include a patient forum for the presentation and discussion of patient insights and concerns. We are excited about the prospects for continued progress toward a cure for epilepsy, but it is important to pursue this goal through a systematic effort to define and understand the many forms of epilepsy, and to take advantage of opportunities to develop and improve treatments. A major fiscal year 2000 initiative will deal with the genetics of epilepsy, beginning with the workshop on genetics of epilepsy sponsored by NINDS on March 4–5, 1999.

Question. Can you tell me how long it might take before we achieve some significant results in treating and curing intractable epilepsy?

Answer. Predictions about treatments and cures are difficult. The term "intractable epilepsy" does not describe a single disease but several forms of epilepsy affecting specific subgroups of patients. I am optimistic that we will see significant progress in specific areas, but it is important to remember that epilepsy is a very complex group of diseases. The forms that are clearly inherited through the action of single genes are quite rare, and the more common forms involve the actions and interactions of many genes and external factors. Still, unraveling the genetic bases of epilepsy will almost certainly suggest new targets for treatment. Modern techniques for drug development and improvements in imaging will pay off in terms of new drugs that act on disease pathways we cannot target now, and improved ability to localize the seizure focus prior to surgery. I think it is safe to say that within the next five years we will reduce the proportion of epilepsy cases regarded as "intractable."

ALZHEIMER'S DISEASE RESEARCH AT NIH

Question. As you know, approximately 4 million people suffer from Alzheimer's disease, including over 100,000 people in Wisconsin. That number is expected to increase to over 14 million by the end of the next century. American families spend over $100 billion each year on Alzheimer's disease, and over half of nursing home patients have Alzheimer's or a related disease. Given the tremendous suffering that Alzheimer's patients and their families endure, plus the high costs of treating Alzheimer's, does NIH plan to spend more resources on Alzheimer's disease? What specific steps do you plan to take to ensure that Alzheimer's research remains a top priority at NIH?

Answer. Between fiscal year 1998 and fiscal year 2000, funding for Alzheimer's disease has increased by 15 percent across NIH. In response to a request from Congress, the NIH has developed a blueprint for preventing Alzheimer's disease, the Alzheimer's Disease Prevention Initiative. This initiative emphasizes that commitment to Alzheimer's research remains a high priority at NIH. It outlines NIH strategies for ensuring that progress in understanding the basic biology of Alzheimer's disease leads as rapidly as possible to development of appropriate interventions, and

their eventual testing in clinical trials. As an indication of progress, the first NIH-funded trial to try to slow or prevent development of Alzheimer's disease is starting in March 1999. The initiative also outlines measures to alleviate suffering for persons who already have Alzheimer's disease and their caregivers. One important aspect of the initiative is cultivation of optimal interactions among the NIH, other Federal agencies, the private sector, and philanthropic organizations in developing strategies to defeat this disease before it exacts an even greater toll on our aging population.

L-CARNITINE TREATMENT

Question. A physician in Appleton, Wisconsin, recently contacted me regarding an amino acid treatment—called L-carnitine—that combats malnutrition for kidney patients undergoing dialysis. Medicare does not cover it in Wisconsin. This physician has had a great deal of success with L-carnitine, and believes Medicare should cover it in the future. Has the NIH conducted research on L-carnitine to determine its effectiveness in combating malnutrition? If so, what findings were made? Does NIH have plans to study this further?

Answer. There is a high mortality rate in the dialysis population, and a particularly adverse impact of malnutrition on mortality and morbidity in this population. L-carnitine is an amino acid that some physicians believe can reverse malnutrition in some patients on dialysis, though no controlled clinical trials have been conducted that would provide definitive information. L-carnitine is available as an intravenous preparation. When prescribed for patients, reimbursement for this treatment is not uniform from state to state. The Health Care Financing Administration has left reimbursement decisions to the discretion of the local Medicare carriers. Therefore, some carriers, with appropriate justification from the physician, pay for its use. Others, such as the carrier in Wisconsin, will not pay for it, even with justification.

Currently, there is inadequate data on nutrition in dialysis patients. This is an important area for research since malnutrition is a major cause of mortality and morbidity in dialysis patients. The NIDDK will be investigating this issue as part of a new initiative planned for the future. The initiative will deal with nutritional intervention in dialysis patients to improve morbidity and mortality; L-carnitine may be a supplement.

SUBCOMMITTEE RECESS

Senator SPECTER. The subcommittee will stand in recess to reconvene at 9:30 a.m., Wednesday, March 3 in room SD–138. At that time we will hear testimony from the Honorable Richard Riley, the Secretary of Education.

[Whereupon, at 11:28 a.m., Tuesday, February 23, the subcommittee was recessed, to reconvene at 9:30 a.m., Wednesday, March 3.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2000

WEDNESDAY, MARCH 3, 1999

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:30 a.m., in room SD–138, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Gregg, Stevens, Kyl, Harkin, Kohl, Murray, and Feinstein.

DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

STATEMENT OF HON. RICHARD W. RILEY, SECRETARY

ACCOMPANIED BY:
MIKE SMITH, ACTING DEPUTY SECRETARY
TOM SKELLY, DIRECTOR, BUDGET SERVICE

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. We will commence this hearing for the subcommittee on Labor, Health Human Services, and Education. And this morning we have the distinguished Secretary of Education, Richard Riley, and we welcome you back, Mr. Secretary.

DISCRETIONARY BUDGET REQUEST AND SPENDING CAPS

The Department of Education has a discretionary budget this year totaling some $34.7 billion which is an increase of $1.2 billion, or 3.7 percent. My very able staff has prepared charts, Mr. Secretary, which shows some $18 billion in offsets which I think lack a sense of reality, and the subcommittee is going to be faced with some very tough choices with respect to allocation of funds—really disregarding those $18 billion in offsets which will require some $2.7 billion in cuts from the subcommittee. That is on top of the very difficult problems we face looking for an increase in funding for the National Institutes of Health and the problems with funding education on so many key points. So we would appreciate your advice as to where you would look for pro rata cuts on education without the projected $18 billion in savings.

The issue of the caps is always a complicated one. And if the President chooses to take a leadership role to urge the raising of the caps, that would be one thing. But in the absence there, we are going to be facing very, very tight budget constraints.

Without objection, my full statement will be made a part of the record. We have the honor of having the chairman of the full committee here this morning.

Senator Stevens, would you care to make an opening comment or two.

OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. I do. I thank you very much, and I do welcome the Secretary, an old friend here.

Mr. Chairman, I have my own defense hearing this morning. I just have a couple of things to talk to you about, Mr. Secretary, and I would like to put some direct questions in the record on these.

FETAL ALCOHOL SYNDROME AND SPECIAL EDUCATION

I was surprised to find out last fall when I had an education conference in Alaska with our commissioner and many of the people involved in PTA's and parents and the school districts of our State that because of the rising rates of fetal alcohol syndrome and fetal alcohol effect in our State, special education has taken on special meaning.

An estimated 25 percent of our students in our largest school district that are really special ed students. I do not think anyone has those statistics that we now face. And I would like to ask our Alaska Education Commissioner to convene a statewide task force to develop a pilot project for our State that would cut through the redtape and see if we could become a test bed for systems to deal with this problem.

The problem is not just dealing with special ed, but also it is the medical problem of trying to see if it is possible through education and health techniques to reverse those effects.

My question that I have asked you in these items I am going to put in the record is whether or not you would cooperate with us and see if the Department—your department is willing to make Alaska into a test bed for that type of special education. I do not need an answer now. I am just making an opening statement. I do not want to take too long.

INTEGRATING EDUCATION AND HEALTH DISTANCE LEARNING

One other one is that we have established a telehealth or telemedicine initiative in our State. We have the cooperation of all of the Federal agencies. We are going to have a statewide telehealth plan that merges Federal, State, and local efforts to use the initiatives that we can with telecommunications to provide better health care at lower cost.

We now see that a similar problem exists with regard to education. And we want to move on, as we develop the telemedicine, telehealth approach, to see if we can develop and coordinate a statewide tele-education approach.

There again, we now have the State working with my office and we have the University of Alaska, which is the State university, working with us. We would like to develop a statewide plan and eventually merge the telecommunications concepts of health and education.

I would like to see if your department would be willing to work on distance learning concepts that integrate with other concepts such as health.

BRAIN DEVELOPMENT AND EARLY CHILDHOOD EDUCATION

Last, we have been working with the "Decade of the Brain" people, and one of the things that has really made an impact on me is early brain development and the importance of some types of stimulation for young children from birth through 3 years.

It is, as one of them said in a construction analogy, the brain builds a small foundation or a big one in that time. And we believe that there should be something that we put into effect dealing with parenting education and preparing parents for what they must do in those first 3 years in order to stimulate those brains so that they will, in fact, be receptive to the education techniques such as those in Healthy Start and Head Start.

I would like to talk to you and see if you and Secretary Shalala would cooperate with us to, again, develop a pilot project—it need not be in Alaska, but I hope it would be—but to try and see if we can develop the techniques for parenting education, to prepare parents for the job they must complete during those first 3 years.

FETAL ALCOHOL SYNDROME

I have taken too much of my time. I look forward to talking to you about these questions I am going to put in the record. I think particularly the fetal alcohol syndrome, Dick, is the worst thing I have run into in my life. I cannot tell you how much it saddens me to see those statistics come into our State, and we must find some way to reverse that in the future.

But right now we are dealing with the present and the statistics are just overwhelming right now. I look forward to talking to you about it and thank you very much. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Stevens. Senator Harkin, distinguished ranking member.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Thank you very much, Mr. Chairman. I am pleased to join you and the members of the committee in welcoming Secretary Riley back to the subcommittee and look forward to our discussion about the fiscal year 2000 budget for the Department of Education.

Before I do that, I was just reviewing with my staff over the last few days sort of the past, where we have been in the past, where we are now, and looking at the budget for next year. And I just was thinking about where we were.

GOOD NEWS ABOUT EDUCATION

For years the only news we got concerning education was bad news. Test scores were falling, student loan defaults were rising, confidence in American education was badly shaken. For the first time in a long time we are beginning to see significant reversals in these troubling areas.

After declining for years, reading scores are beginning to improve. On a recent international test, U.S. 4th graders outperformed their peers from all other nations except one, Finland.

A decade ago spiraling student loan defaults were threatening the existence of the student loan program. That default rate has been cut by more than a half. It now stands at less than 10 percent. It is still too high, but what a heck of an improvement.

Finally, we are beginning to see evidence, Mr. Secretary, that reforms made to the Title I program in 1994, reforms that were undertaken with your leadership, are now beginning to show very positive results.

Mr. Secretary, I know you to be a modest person. But, in the words of my teenage daughter, I think your stewardship of this Department has been awesome, just simply awesome.

And so I just want to compliment you and tell you that I just think you have done a great job. You should be rightly proud of the role that you have played in achieving these results that I just talked about.

EDUCATION—A LIFE LONG PROCESS

I know that, Mr. Secretary, in my conversations with you that we do share a view that education is a lifetime process. It is not something that begins at one point and ends at one point. But, in fact, it begins at birth and continues for our entire lifetimes.

There are provisions in the President's 2000 budget which make that clear. I applaud the additional investments in early intervention programs for children with disabilities and enhanced commitment to adult education.

ESEA REAUTHORIZATION

As we proceed later on in this year with the reauthorization—I sit on the authorizing committee with the Elementary and Secondary Education Act reauthorization—I am wondering if we might not want to revisit what the definition of elementary education is. Maybe it should start before kindergarten.

Maybe we ought to just break out of the mold and think about early elementary education and secondary education. I just bring that out because I just want you to know some of the things I will be looking at in terms of the reauthorization process.

FISCAL RESOURCES NEEDED FOR EDUCATION

Now, I must admit, however, I think we are going to have to do something with this education. The amount of money that is in this budget this year, the 3.7-percent increase is a great blow compared to the 12-percent increase we had last year.

And I believe we are going to have to do something to get money in here. I say that with the chairman—he has already left. The full

chairman of the committee was here. We need more allocations to this subcommittee if we are going to meet the obligations that we have out there.

So I just want to make those points to Mr. Chairman. We have worked on a bipartisan basis to provide some historic increases for education. And these increases were possible because we all worked together on this. We made these significant investments. So I hope we do not back down now.

I will be having more to say later on about the trade-off between the budget that the President sent down to us. I notice that there is, over the next 5 years, a proposal to increase defense spending $112 billion—$112 billion. Now that is an interesting number, Mr. Chairman, because that is exactly the same number the experts tell us that we need to rebuild and remodel our crumbling schools all across America, the exact same number.

I believe in a strong defense, but I believe in a commonsense defense. And I think there is going to have to be some trade-offs here about really what is most important for the security of our Nation in the future. So with the walls down—these fire walls down, I think we are going to have to take a look at maybe cutting down on one and building up on the other.

PREPARED STATEMENT

With that, I will yield my time. Thank you very much, Mr. Secretary. Again, I applaud you for what you have done. You have done a great job.

Senator SPECTER. Thank you very much, Senator Harkin.

[The statement follows:]

PREPARED STATEMENT OF SENATOR TOM HARKIN

Mr. Chairman, I am pleased to join you in welcoming Secretary Riley to the subcommittee and look forward to our discussion about the fiscal year 2000 budget for the Department of Education.

I have been around here a long time. I've seen Secretaries come, and I've seen them go. But no one can match the dedication and leadership we have from the present Secretary of Education. Secretary Riley, you have done an outstanding job.

For years, the only news we got concerning education was bad news. Test scores were falling. Student loan defaults were rising. And confidence in American education was badly shaken.

For the first time in a long time, we are beginning to see significant reversals in those troubling trends.

—After declining for years, reading scores have begun to improve and U.S. 4th graders outperformed their peers from all other nations on a recent international assessment, except one [Finland].

—A decade ago, spiraling student loan defaults were threatening the existence of the student loan program. That rate has been cut by more than half and now stands at less than 10 percent. Still too high, but a dramatic improvement.

—Finally, we are beginning to see evidence that reforms made to the Title I program in 1994, reforms that were undertaken with your leadership, are beginning to show results.

I don't mean to suggest that you have accomplished all of this single-handedly, but you have played an important role for the past 6 years.

Mr. Secretary, you have been a relentless advocate for American education and our nation's children and are to be commended for your strong leadership.

We share an important view, that education is a process that begins at birth and must continue for our lifetimes. There are provisions in the President's fiscal year 2000 budget which make that clear. I applaud the additional investments in early intervention programs for children with disabilities and the enhanced commitment to adult education.

Over the years, I have been impressed with the strong education budgets from the Clinton Administration. But, I must tell you, I am, quite frankly, disappointed by this year's budget for education.

You are recommending a $1.2 billion increase in education over last year—an increase of only 3.7 percent. That is in sharp contrast to the 12 percent increase of last year.

I clearly understand the pressure facing the Administration in putting this year's budget together. The constraints placed on discretionary spending are very tight. As a result, the fiscal year 2000 budget provides a very modest increase for education. In my view, too modest.

Unfortunately, education was shortchanged in order to provide a $12 billion increase in Pentagon spending next year and an increase of $112 billion over the next 6 years. I can't help but be struck by the irony of that figure—$112 billion—because that is precisely the amount of money GAO tells us we need to modernize our nation's crumbling schools.

While I appreciate the investments in early intervention programs for children with disabilities, I am, however very disappointed that there is no increase for the special education grants to states. We are fulfilling only one quarter of the goal we set in 1975 and I would like to see continued improvement in funding for special education. We need to redouble our bipartisan efforts to help school districts meet their obligation to educate students with disabilities.

I don't want to go through every line of the budget, but want to note one other major concern about the relatively small increase for the second installment in the plan to hire 100,000 new teachers. I hope we can reauthorize this program and also work to increase funding for the upcoming year.

Mr. Chairman, over the past few years, we have worked, on a bipartisan basis to provide historic increases for education. Those increases were possible because we were first challenged, by you, Mr. Secretary to make significant investments in the education of our children and we responded.

But we must not lose sight of the fact that a strong budget for education from your end of Pennsylvania Avenue has made it possible for those of us at this end to provide those historic increases.

Mr. Secretary, I look forward to your testimony today and look forward to working with you, Chairman Specter, and other members of the subcommittee to fashion a budget for education which truly makes education our nation's top priority.

PREPARED STATEMENTS OF SENATOR ROBERT C. BYRD AND SENATOR LARRY CRAIG

SENATOR SPECTER. We have received prepared statements from Senator Byrd and Senator Craig which will be inserted into the record at this point.

[The statements follow:]

PREPARED STATEMENT OF SENATOR ROBERT C. BYRD

Mr. Chairman, Senator Harkin, thank you for holding this hearing today to discuss the Department of Education budget for fiscal year 2000. I extend my appreciation to both of you for all of your hard work and commitment in the area of education.

Although I am not a member of this subcommittee, I am extremely committed to the notion of lifelong learning, and I am deeply troubled by our nation's ailing public education system. I appreciate the Subcommittee's graciousness in permitting me to speak briefly.

Mr. Secretary, I welcome you today. With the Elementary and Secondary Education Act reauthorization looming in the months ahead, I would like to raise an issue of great concern to me, which is shared by many parents nationwide—that is, education accountability. I find it ironic that in an age where a wealth of information abounds about any imaginable field, precious little information exists about the performance of our nation's schools.

Education Week, in partnership with two public opinion research firms, recently published an issue entitled "Reporting Results" that discusses this new buzzword of 1999—accountability. While I find encouraging the fact, as reported in Education Week, that thirty-six states are expected to issue school accountability data or "report cards" this year, that practice, it seems to me, should be undertaken by all fifty states.

Furthermore, of the thirty-six states that will have report cards in 1999, only thirteen states ensure that the report cards actually get sent home to parents and few include all the information that parents actually want to see most. Moreover, the information they provide rarely finds its way to the community at large which has an interest in the education of its young people. I am baffled by this phenomenon! Why go through the process of creating such a document for it to end up as yet another soiled piece of paper in the garbage can?

Of all the decisions in life that a parent has to make, the decision about where to send a child to school is perhaps one of the most difficult and time-consuming. And I find it unbelievable to think that parents often, for the lack of better information, rely upon word-of-mouth to make such important decisions. Where are the numbers on student achievement, test scores, teacher certification, and graduation rates? Parents need to have this information before them as a key resource for making an informed decision.

I feel for parents who, despite their best efforts to learn about the quality of their local schools, cross their fingers as they send their children off each day in the hope that their children will be spending those hours in an enriching and safe environment. I find it terribly disconcerting that the quality of our schools in different corners of the same community can differ so dramatically as to force families to move from neighborhood to neighborhood on the trail of the best schools. I find it appalling that so many families have felt forced to give up on public schools in favor of private schools and home schooling.

Mr. Secretary, I believe that more information about education is the key to unlocking this trend burdening so many families today. With more information, and I am talking about the real stuff—test scores, teacher qualifications, graduation rates, tracking of students from grade school into college and after—parents will have substantive data at their fingertips to truly determine what is in the best interest of their child and family as a whole.

Competition is at the heart of creating better schools for the nation.

By forcing schools to annually report on performance data, such as test scores and other quantitative measures, teacher qualifications, and safety indicators, parents will have a framework for weighing one school against another, and communities will have data they need to achieve improvements in their school systems. As Education Week pointed out in its report, so many of the report cards that actually make their way into a parents' hands are difficult to read, with extraneous information of little benefit to educators and parents. Mr. Secretary, there needs to be uniformity in gathering key data that parents are seeking and a model that all parents can follow. Holding schools accountable for the students they are producing and the teachers they have chosen, while making this information readily available to parents, will turn up the heat on schools, and apply much long-needed pressure to those at the helm to focus on teacher qualifications and curriculum requirements.

But test scores and other achievement data will mean little to parents if we continue this so-called trend of "teaching to the test." What good will come of teaching students skills simply to ace a standardized test? In 1984, I established what was later named the Robert C. Byrd Honors Scholarship to recognize and reward high school seniors with excellent academic records. My intention was, and remains, to single out those select students who thrive on learning for learning's sake alone, not simply for an "A" letter grade. Mr. Secretary, if we hope to produce well-rounded students prepared for the challenges ahead in today's workforce, schools must begin to test drive the curriculum and stop allowing the curriculum to drive the test.

Education accountability is just one area of education that I hope the Subcommittee, the authorizing committee, and the Administration will look at seriously during the Elementary and Secondary Act reauthorization. I thank the Chairman for giving me this opportunity to speak and I look forward to a successful appropriations process for fiscal year 2000. I would like to follow my statement with a few questions for the Secretary. I then request that the remainder of my questions be submitted for the Record.

PREPARED STATEMENT OF SENATOR LARRY E. CRAIG

Mr. Chairman, I thank you for holding this hearing today. Education is one of our nation's top priorities and should be a focus of everyone's attention. While there are many issues I could discuss today, I want to address one in particular—impact aid.

Impact aid is a recurring issue. It seems that every year the President proposes to slash and weaken the impact aid budget, while Congress recognizes the impor-

tance of it and works to strengthen it. Again, the Clinton Administration has chosen to make detrimental changes to the impact aid program.

Those of us who live in the West are all too familiar with the impact that the federal government has on our lives. When the federal government owns over sixty percent of the land, such as my home state of Idaho, it can't help but affect individual lives and the local economy. However, the President seems to believe that only individuals who live and work on federal lands impact local schools. This could not be further from the truth.

Schools receive a large portion of their funding from local property taxes. When land is removed from the tax base, this affects not only the schools but local governments. To compensate for this, schools must either raise taxes or decrease services. Both of these are unacceptable answers. The federal government should be a good neighbor, which is exactly why the impact aid program was created. To shift its focus away from the impact of federal lands and facilities and to cut its funding is just plain wrong.

As we work through the budget and appropriate money for fiscal year 2000, I hope that we will consider raising the funding for impact aid to a minimum of $864 million, the amount for fiscal year 1999 and ensure that local schools receive funding for both "a" and "b" students and for federal lands which erode the local tax base.

Again, thank you, Mr. Chairman, for holding this hearing today. I look forward to working with you and the rest of the committee as we craft the fiscal year 2000 budget for the Department of Education.

SUMMARY STATEMENT OF HON. RICHARD W. RILEY

Senator SPECTER. Frequently we will have opening statements, but you have drawn such a crowd this morning, Mr. Secretary, eight members here at this hour that we are going to reserve the portion of the opening statements to the rounds of questioning and go directly to your testimony.

Thank you for joining us and we look forward to your statement. Your full statement will be made a part of the record, Secretary Riley. So to the extent you can summarize, leaving maximum time for questions and answers, we would appreciate it.

Secretary RILEY. That is fine. Thank you, sir, if you would do that. I have Mike Smith with me, the Acting Deputy Secretary, and Tom Skelly, the Director of Budget Service.

I want to begin by thanking you, Mr. Chairman, Senator Harkin, and all the members of this committee for your strong support of education over the years. I appreciate your statement and I appreciate the inquiries of Senator Stevens.

I think together, working together, we are beginning to make the investments that are needed to prepare all Americans for this exciting, challenging future. And, if I might, let me cite a few, very briefly.

RAISING STANDARDS AND GOALS 2000

First, raising standards. And I am strong on standards, as you know, one of the most important parts of any improvement effort. With the help of Goals 2000, 48 states have developed more challenging State standards and two other States have encouraged rigorous development of locally developed standards.

The General Accounting Office recently reported that State officials—this is State officials—were asked about that and they said this about Goals 2000: A significant factor in promoting their educational reform efforts. They are very positive about it, and I think that has stood well.

AMERICA READS CHALLENGE

Second, as a result of the President's American Reads Challenge, over 21,000 college students in the Federal Work-Study Program are tutoring youngsters in reading. Their work, along with the improvements that we have made in Title I, will build on progress that we are making in reading.

READING IMPROVEMENT

The latest NAEP study found that reading scores, as was pointed out, reversed their decline and rose in all three grades tested between 1994 and 1998. And that is the first time all three grades—4th, 8th and 12th—showed improvement in 30 years.

The additional resources that we are asking for the Reading Excellence Act, and the additional changes that we are proposing in Title I will help keep moving us in that direction. It is the right direction to go.

ACCESS TO COMPUTERS AND THE INTERNET

Third, the Federal Government is playing a key role in helping all children have access to computers and the Internet in all schools. The E-rate discounts are critical to reaching our goal of connecting every classroom to the information superhighway.

A recent report showed some 89 percent of the schools are connected. That is the first stage. Some 51 percent of classrooms are connected and that is up from 14 percent just several months ago.

Federal resources account for 25 to 30 percent of all the money that we spend on educational technology in our schools. And I think we need to be certain not to lose that technological edge. That is why we have $450 million in our technology budget request, an increase of $25 million. And I think that is so important to help pay for hardware, and educational software, and to train teachers to use technology in the classroom.

And, finally, in higher education, the new Hope and Lifetime Learning tax credits will give 12.7 million students and their families—12.7 million—this year, over $7 million to help them pay for college expenses.

PELL GRANT AND WORK-STUDY BUDGET INCREASES

These tax credits, along with our request for a $125 increase in the maximum Pell Grant award and a $64 million increase in the Work-Study program, will open the doors for college even wider.

GEAR UP INITIATIVE

We also seek to double the funding to $240 million for the exciting GEAR UP initiative. GEAR UP will provide mentoring, tutoring and career counseling for about 381,000 students in nearly 1,000 high-poverty middle schools—and, Mr. Chairman, I appreciate your strong support for that initiative. By investing in education and working to lift the burden of debt from our children and grandchildren, we have kept faith, I think, with future generations.

ELEMENTARY AND SECONDARY EDUCATION PROGRAMS REQUESTS

In addition to the initiatives that I have mentioned, this budget would help end social promotion, help turn around low-performing schools, reduce class size, modernize schools, raise the quality of teaching, expand after-school programs, help improve literacy, accelerate the public charter school movement and help new Americans learn English.

ESEA REAUTHORIZATION—STRENGTHENING ACCOUNTABILITY

As President Clinton has stated, strengthening accountability will be a key focus of our efforts to reauthorize the Elementary and Secondary Education Act this year. The President's budget backs this effort with increases in two areas.

AFTER-SCHOOL AND SUMMER SCHOOL PROGRAMS

First, to help end social promotion. We are asking for $600 million for after-school and summer school programs to help children catch up academically. Social promotion simply does not work, but holding children back will not work either. We must help children make the grade and this proposal which triples last year's request will expand learning opportunities for over 1.1 million students.

TITLE I ACCOUNTABILITY PROVISIONS

Second, the request for Title I grants contains $200 million to turnaround low performing schools, to help turn them around. Contrary to what some people say, we do not think it expands Federal control. We simply want to press for the implementation of Title I accountability provisions that the Congress put in the ESEA authorization several years ago.

COMPREHENSIVE SCHOOL REFORM AND CHARTER SCHOOLS

We are also requesting $175 million for the Comprehensive School Reform Demonstration program. We are calling for $130 million for public charter schools, an increase of $30 million, to support up to 2,200 charter schools. There was only one charter school in America when the President took office. And public charter schools give parents real choice with accountability and without bleeding public schools of vital funds.

CLASS SIZE REDUCTION INITIATIVE

Another major emphasis in the budget is better teaching. It contains the second installment of our initiative to recruit and prepare 100,000 good new teachers in order to help reduce class size in grades one through three to a nationwide average of 18. The request includes $1.4 billion to hire 38,000 more teachers in the second year of the 7-year program.

The President has asked the Senate to authorize $11.4 billion to hire the full complement of 100,000 teachers in the next 6 years, and I urge the Senate to take this step to assure communities that Congress will provide this continued support.

SCHOOL CONSTRUCTION INCENTIVES

Even though it is not part of our discretionary request, I want to highlight the school construction and modernization tax incentive. Teaching and learning suffer in schools that are in disrepair, that are overcrowded, that are so old they cannot accommodate new technology. And the President's proposal would support almost $25 billion in interest-free bonds to repair, build or modernize some 6,000 schools.

PROFESSIONAL DEVELOPMENT—BILINGUAL AND INDIAN EDUCATION

The budget also includes $115 million, an increase of $40 million, to help, among other things, to reduce shortages of qualified teachers in high-poverty school districts.

A $25 million increase for Bilingual Education Professional Development will help address the shortage of good bilingual and English-as-a-second-language teachers, and $10 million for an American Indian Teacher Corps Initiative program would recruit and train a thousand new Indian teachers over the next 5 years to work in Native American communities.

ESEA REAUTHORIZATION CONSOLIDATION PROPOSAL

Even though ESEA reauthorization does not come under this budget, the members here should know that our proposal will include an initiative to improve teaching and put high standards to work in the classroom. This initiative calls for building on and consolidating the current Goals 2000, Title II Eisenhower program, and Title VI Innovative Education Strategies State Grants program.

SAFE AND DRUG-FREE SCHOOLS

In the critically important area of school safety, our $439 million request for Safe and Drug-Free Schools State grants would target larger grants to school districts with the most severe problems by requiring States to distribute 30 percent of their allocations as competitive grants to those of the neediest areas.

DRUG AND VIOLENCE PREVENTION COORDINATOR INITIATIVE

We also propose $50 million, an increase of $15 million, to pay for 1,300 antidrug coordinators for 6,500 middle schools.

ADULT EDUCATION

And, finally, the President's budget includes significant increases for programs to help adult Americans to master literacy and other basic skills. Adult education State grants would increase by $123 million, or 28 percent, to expand programs to help immigrant and limited English proficient adults learn English.

I have quoted, Mr. Chairman, John Stanford before. He was a brilliant superintendent of Seattle who passed away and left such a mark in that city bringing people together for education. I have never seen anybody so effective. He died recently as you know. Senator Gorton who was here, of course, is very familiar with him also.

PREPARED STATEMENT

John had this saying, and I close with it, "The victory," he says, "is in the classroom." I think we have done a good job with standards, in getting the States involved in standards in a big way. But standards must move into the classroom in order to make a big difference.

I believe that this budget will go a long way toward giving us that kind of victory in the classroom that John Stanford talked about.

Thank you very much for giving me the chance to make this statement.

Senator SPECTER. Thank you very much, Mr. Secretary.

[The statement follows:]

PREPARED STATEMENT OF HON. RICHARD W. RILEY

Mr. Chairman and members of the subcommittee: I am pleased to have this opportunity to talk about President Clinton's fiscal year 2000 budget request for the Department of Education. I want to begin by thanking you, Mr. Chairman, as well as other Members of this Subcommittee, for your strong support of education over the past several years. Together I think we have made real progress in making the kind of investments in education needed to help prepare all Americans for the challenges we face in the new century that lies just around the corner.

In particular, our joint effort to help States and communities to set academic standards for all children has been a tremendous success. With the help of programs like Goals 2000, 48 States have developed state-level standards, and two States have pushed for standards at the local level. I believe the effort to raise standards has much to do with the positive results of the latest reading scores on the National Assessment of Educational Progress (NAEP).

In 1998, the national scores in the NAEP reading assessment increased at all three grades tested—4, 8, and 12—for the first time. And unlike 4 years ago, when some States were losing ground, the 1998 NAEP state-level results for reading showed that no State fell further behind, while 10 States showed solid progress. I believe these latest NAEP results show we are on the right track in improving educational achievement in America.

I remain concerned, however, that this progress has been uneven, particularly in high-poverty schools. The President's 2000 budget for education is designed to improve student achievement by accelerating change and increasing accountability based on these State and local standards.

The President's request would help end social promotion, reduce class size, modernize schools, raise the quality of teaching, improve literacy and help new Americans learn English, and provide new pathways to college for disadvantaged students.

SCHOOL CONSTRUCTION AND CLASS-SIZE REDUCTION

Before I describe our discretionary request, I want to highlight the School Construction and Modernization tax incentive, which the President is proposing for the third year in a row. Students cannot learn—and teachers cannot teach—to high standards in falling down, overcrowded classrooms. The President's proposal would support almost $25 billion in interest-free bonds to help build or modernize up to 6,000 schools.

Modernizing classrooms—and building more of them—goes hand-in-hand with the Class-Size Reduction program launched just last fall. The goal is to recruit and train 100,000 new teachers to help school districts reduce class sizes in grades 1–3 to a nationwide average of just 18 students. The 2000 request includes $1.4 billion to help school districts hire a total of 38,000 teachers in the second year of the program, an increase of 8,000 over the 1999 level. There's no better way to rapidly improve student achievement than to put highly trained teachers into small classes where they can provide the individual attention students need to reach high standards.

The budget also provides $461 million for Goals 2000 State grants to help some 5,000 school districts continue standards-based reform efforts. I should note here that a recent report from the General Accounting Office found that State officials considered Goals 2000 to be a "catalyst" and "a significant factor in promoting their

education reform efforts." That is exactly what we hoped for when we worked with Congress to create this program 5 years ago, so I am happy to see that it is working as intended.

Another catalyst for change in our schools is technology. Our request includes $450 million for the Technology Literacy Challenge Fund, an increase of $25 million to help pay for hardware, train teachers to use technology in the classroom, and develop and buy educational software.

IMPROVING ACCOUNTABILITY

As you heard in the State of the Union Address, strengthening accountability will be a key focus of our efforts to reauthorize the Elementary and Secondary Education Act (ESEA) over the coming year. The President's budget backs this effort with major increases in two areas.

First, to help end the practice of social promotion, we are asking for $600 million for 21st Century Community Learning Centers, an increase of $400 million to help some 2,000 additional school districts create or expand after-school and summer programs that can help students catch up academically. This request would serve approximately 1.1 million students of the estimated 15 million school-aged children who go home alone after school each day. In places like Chicago, after-school programs have helped to end social promotion by strengthening academic achievement, and not by retaining students in grade.

Second, the request for Title I Grants to Local Educational Agencies contains $200 million to help turn around failing schools. Contrary to several reports that I have seen in the news media, our goal here is not to expand Federal control over local schools, but to help States and school districts implement the Title I accountability provisions established by Congress during the last ESEA reauthorization.

One of the best ways to bring about real change and turn around failing schools is through research-based reforms. That is why our request includes $175 million for the Comprehensive School Reform Demonstrations program, an increase of $30 million to help an additional 560 schools carry out research-based school improvement. We would also increase funding for educational research by $45 million, for a total of $109 million, to help meet the growing need for research-based information on what works in education. The research request includes $25 million to continue an interagency effort—involving the National Science Foundation and the National Institute of Child Health and Human Development—that will focus on using technology to improve school readiness, K–3 instructional practices, and K–12 teacher preparation in the areas of reading and mathematics.

The charter school movement continues to bring together teachers, parents, and community leaders to reinvent public schools and turn around lagging student achievement. The budget provides $130 million for Charter Schools, an increase of $30 million, to support up to 2,200 new or redesigned schools that offer innovative approaches in exchange for greater accountability for student achievement.

The 2000 request also continues support for mastering the basics, including $8 billion for Title I Grants to Local Educational Agencies and $286 million for the 2nd year of the new Reading Excellence program, which helps all children to read well and independently by the end of the third grade. A new $50 million Special Education Primary Education Intervention program would help school districts meet the needs of children aged 5 through 9 who have marked difficulty learning to read or who have behavioral problems. The budget also would double funds for improving writing skills to $14 million, while providing $6.7 million for America Counts, a new initiative to ensure that middle school students master the fundamentals of algebra and geometry.

BETTER TEACHING FOR ALL STUDENTS

Another major emphasis in the 2000 budget is on better teaching for all students. Raising the bar for teachers will be especially difficult in view of the estimated shortage of 2 million teachers over the next 10 years, but it is essential if we are to improve student achievement.

Teacher quality also will be a key priority in the Administration's proposal to reauthorize the Elementary and Secondary Education Act of 1965. Now that challenging academic standards have been established in every State, we see improving classroom instruction as essential to driving these standards down to the classroom level.

Our ESEA reauthorization proposal will include a new initiative, called Quality Teachers and High Standards in Every Classroom, that would help States and school districts continue the work of aligning instruction with State standards and assessments while focusing most resources on improving teacher quality through

high-quality professional development. This new initiative, which would not take effect until fiscal year 2001, would replace the current Goals 2000, Title II Eisenhower Professional Development State Grants, and Title VI Innovative Education Program Strategies State Grants programs.

For fiscal year 2000, the President's budget includes $335 million for Eisenhower Professional Development State Grants, which help States and school districts provide intensive professional development in all the core academic subjects. The newly authorized Teacher Quality Enhancement Grant program would receive a $40 million increase, for a total of $115 million. These funds would help States improve the quality of their teaching force, strengthen the capacity of educators to design effective teacher education programs, and reduce shortages of qualified teachers in high-poverty school districts.

The $1.4 billion Class Size Reduction program also is an important part of the teacher quality effort, because it allows school districts to use up to 15 percent of their allocations to improve teacher quality through such activities as testing new teachers for academic content knowledge and professional development for current teachers.

A $25 million increase for Bilingual Education Professional Development would help address the critical national shortage of well-prepared bilingual and English-as-a-second-language (ESL) teachers. And a new $10 million American Indian Teacher Corps program would recruit and train 1,000 new Indian teachers over the next 5 years to work in Native American communities.

IMPROVING SCHOOL SAFETY

School safety is a concern of teachers, parents, and students alike. The President's budget includes significant support for a wide range of efforts to keep schools safe and drug-free. The $439 million request for Safe and Drug-Free Schools State grants would target larger grants to school districts with the most severe problems by requiring States to distribute 30 percent of their allocations as competitive grants.

We would also increase funding for the Coordinator Initiative, which would put a skilled program coordinator in nearly half of all middle schools to help develop and implement effective drug and violence prevention strategies. And a new $12 million initiative known as Project SERV (School Emergency Response to Violence) would strengthen current ad hoc efforts to provide emergency assistance to schools affected by violence or other traumatic incidents.

EXPANDING OPPORTUNITIES FOR POSTSECONDARY EDUCATION

One of the most important achievements highlighted by President Clinton in his State of the Union Address was the simple statement that "we have finally opened the doors of college to all Americans." Over the past 6 years, larger Pell grants, expanded work-study opportunities, lower borrowing costs on student loans, and generous Hope and Lifetime Learning tax credits have made college possible for all who qualify.

Paying for college is still a difficult burden, however, especially for low- and middle-income families, and our 2000 budget would help reduce that burden. The maximum Pell Grant, for example, would rise to $3,250, an increase of $125 over the 1999 level. A $64 million increase for Work-Study would fulfill the President's goal of giving 1 million recipients the opportunity to work their way through college. The Work-Study request also would bolster the "America Reads" and "America Counts" initiatives, under which Work-Study recipients serve as reading and math tutors.

Despite the availability of student aid, too few disadvantaged and minority students pursue and complete a postsecondary education. The 2000 budget contains several proposals to increase college-going and college-completion rates for these students.

We would double funding to $240 million for the GEAR UP program, which supports new partnerships between postsecondary institutions and middle schools to help disadvantaged students think about and plan for college early on in middle school. The request would provide early intervention services such as mentoring, tutoring, and career counseling for about 381,000 students in nearly 1,000 high-poverty middle schools. The budget also includes a $30 million increase for TRIO, for a total of $630 million to support outreach and support services extending from middle school through graduate education.

Two new initiatives would encourage students to enter and complete postsecondary education. The $35 million College Completion Challenge Grants program would help postsecondary institutions increase the persistence rate of students who are at risk of dropping out. And the $15 million Preparing for College initiative

would provide vital information to young students and their parents about the importance of higher education and the steps needed to go to college.

IMPROVING THE SKILLS OF ADULT AMERICANS

Finally, the President's budget includes significant increases for programs to help adult Americans master literacy and other basic skills. Adult Education State Grants, for example, would increase by $103 million, or 28 percent, to expand State efforts to help immigrant and other limited English proficient adults—including Hispanics—to learn English, make a successful entry into the workforce, and be part of the American success story.

The request also would provide $70 million to demonstrate methods of providing instruction in English as a second language and civics/life skills to recently immigrated young adults who were never enrolled in American schools and who completed minimal education in their native countries.

Disadvantaged adults also would benefit from a proposed $55 million expansion of the Community-Based Technology Centers program, which helps community residents gain technology skills, take courses on-line, and access on-line job databases by bringing technology to public housing, community centers, libraries, and other community facilities.

I believe the President's budget offers a significant opportunity to bring real change to our schools and enhance lifelong learning for all Americans. I look forward to working with the Subcommittee to make good on this opportunity.

I will be happy to take any questions you may have.

FEDERAL EDUCATION PROGRAMS

Senator SPECTER. Picking up on a conversation which you and I had last week about the number of programs, I note that your Department administers some 171 programs, that there has been a reduction of some 7 programs and an addition of 10 more programs. And I believe that we need to renew the effort to evaluate all of these programs.

We go back historically and find that some Senator at some point or some Member of the House had a special program, and there is a real issue as to whether those programs retain their current vitality. And there is, as you know, Mr. Secretary, a growing sense in the Congress and I think in the country, too, on more block grants and less strings attached to Federal funding. So I would like to put our staffs to work on that and then we can renew that effort with Senators and you personally at a later stage.

SPECIAL EDUCATION FUNDING LEVEL

The issue of special education continues to be a very pressing national priority. And there is a commitment on this mandated program by the Congress to fund 40 percent. That funding had been pretty level at $2.2, $2.3 billion until 3 years ago when we added $780 million and 2 years ago, $700 million and last year $509 million. I know that we are going to be facing additional pressures on special education to find an increase in funding. When we take a look at the total increase for the Department it is $1.2 billion and the request for the 100,000 teachers is some $1.4 billion.

Let me ask you, Mr. Secretary, a threshold question in assessing priorities. How would you compare the responsibility of the Federal Government to increase funding on special education with the issue of additional teachers, evaluating the Federal role versus State and local responsibility on the funding items?

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Secretary RILEY. Mr. Chairman, let me kind of describe what our proposal is this year in the IDEA area that you inquire about.

We have in this proposed budget a $116 million increase in IDEA. It is directed toward prevention, though. $30 million is directed towards children aged 0 to 2. Senator Stevens was inquiring about young children and brain development; fetal syndrome, crack babies, all of the different problems of very young children.

$28 million is for children ages 3 to 5 as they get on into—as they are getting ready for school and then $50 million is for children ages 5 to 9. These amounts are for prevention activities in the IDEA areas.

IMPACT OF CLASS SIZE REDUCTION ON SPECIAL EDUCATION

We think really, though, the support of class size reduction which you refer to will have an enormous effect on the numbers of children in special ed and on helping children with disabilities. Some 75 percent of children with disabilities spend more than 40 percent of their time in a regular classroom. That is important to realize. A regular classroom is very important for disabled children.

AMERICA READS PROGRAM

Also, the America Reads program, goes to the reading issue which is so important for young children.

BUDGET CAPS AND FUNDING CHOICES

Senator SPECTER. Mr. Secretary, you are not suggesting that by increasing the number of teachers that we will be able to cut back our commitment on special ed, though, are you?

Secretary RILEY. I am saying by those things we will cut back, in my judgment, in a good way on the number of children who will go into special ed, and that will affect the cost of special ed. I very strongly support the funding of special ed and, as you know, the funding has increased significantly for IDEA over the last several years, and much of that leadership has come from Congress.

Senator SPECTER. Almost all of it has come from Congress. But if you have a limited number of dollars and have to make a choice between the new teachers and special education, where would you go, Mr. Secretary?

Secretary RILEY. Well, of course, the caps have put kind of an artificial limit on those decisions. And what I would say is that you would have to have a balance in that. I think these issues like school construction, class size, reading and so forth impact on special ed students in a very significant way as well as all other children.

Also, I think the prevention part of special ed is something we should emphasize. I would like to see funds for IDEA raised, but the caps, if we do these other things, of course, prevent that. But if the caps were relieved in some way during the year, I would think IDEA would be one of the priorities that should be considered.

Senator SPECTER. My red light is on. So I will ask another question. But I would ask for your further response to that question.

If the caps are raised, that is a different ball game. If the caps are not raised, we have to make choices. And I would like to have your recommendation if we have to choose one or the other. These are the really two big ticket items. Unless we can cut a lot of programs and save very substantial money, I think we are going to have to make that choice.

And I can understand that you may want to reflect on it some more. But when Senator Harkin and I finally sit down for our recommendations for the subcommittee, we are confronted with that choice.

We have the early bird rule. Senator Feinstein was next in line.

PREPARED STATEMENT

Senator MURRAY. She had to leave. She asked that her statement be put on the record.

Senator SPECTER. Without objection, we will put Senator Feinstein's statement in the record. She may wish perhaps to submit questions for the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR DIANNE FEINSTEIN

Welcome to the Subcommittee, Secretary Riley. I am pleased that this is one of our first hearings this year and that you are one of our first witnesses because it demonstrates how important we think the education challenge is. I also want to thank Chairman Specter and Ranking Minority Member Harkin for scheduling this hearing early in the legislative session.

I am very concerned about the performance of America's students, and to illustrate my concerns, I'd like to share the following problems confronting California:

—Many high-tech employers in California tell me that they cannot find qualified people to hire and must search abroad due to applicants' inadequate skills and preparation.

—Almost half the students entering California State University need remedial education in math and English.

—California's students perform below the national average in math, science, and reading.

—California has 21,000 teachers on emergency credentials at a time when we will need 300,000 more teachers over the next decade because of class size reduction and escalating enrollments.

—California ranks near the bottom of states in the quality of its teaching force because of the high number of uncertified or undertrained teachers, according to a report from the National Commission Teaching and America's Future.

I know, Mr. Secretary, from your February 16 State of America Education speech, that nationally some student test scores are rising. However, we also know that our children are scoring behind their peers in other industrialized countries. The lowest 25 percent of Japanese and South Korean 8th graders outperform the average American student (Organization for Economic Cooperation and Development, November 1998). American students' overall performance was better than only two other countries, Cyprus and South Africa, in the Third International Mathematics and Science Study. In eighth grade math, our students scored well below the international average. These are troubling statistics.

However, I am heartened by some of the initiatives that your Department has introduced. First, I commend you for supporting an end to social promotion, a cause I have supported since coming to the Senate in 1992. I also applaud your endorsement of state achievement standards, high-school exit exams, class size reduction, expanding after-school and summer school programs, strengthening teacher training, ending emergency teaching credentials, paying teachers more, and turning around low-performing schools. These are all important and meaningful steps toward reform.

Nevertheless, your budget increase of $1.2 billion represents a 3.7 percent increase over last year. I'm sure you know that the education community has called for a $5 billion or 15 percent increase in fiscal year 2000. I would hope that we could find a way to increase our investment in education, when, after all, the federal

share of total education spending by your Department is only 8.5 percent. The Committee for Education Funding says that in fiscal year 1999, education spending will be only 2 percent of the federal budget.

I especially want to call your attention to one of my major concerns and that is the ESEA Title I formula. By our calculations, California is home to 13.5 percent of the Title I eligible children, but receives only 11 percent of Title I funds. While the national average for Title I funds per child is $710, California receives $601 in Title I funds per child. Meanwhile, California has a poverty rate that exceeds the national rate and continues to experience a higher growth rate in poor children than most states.

As I understand it, there are 3 factors that hurt California: The fiscal year 1999 appropriations "hold harmless" language, which I urged this subcommittee and the conference committee not to include; the state expenditure factor; and the small state minimum factor.

My view is that the dollars should follow the child, especially in a program designed to provide extra help to disadvantaged children. I believe this is what Congress intended in establishing this program, that funding to a state be based on the number of children served. I hope you will join me in working for changes to carry out that principle.

There is hardly a more important challenge before this Congress than improving American education. A January CNN/USA Today/Gallup poll found that education was Americans' number one choice for how most of the budget surplus should be spent. I believe Americans are demanding reform because they know how important the foundation of a good education is for their children.

I look forward to working with you to implement reforms systemwide, broadly and deeply.

OPENING STATEMENT SENATOR PATTY MURRAY

Senator SPECTER. I believe Senator Murray is next in order of arrival.

Senator MURRAY. Thank you, Mister——

Senator SPECTER. Pardon me, Senator Harkin, you are next.

Senator Murray, the ranking member has yielded.

Senator MURRAY. Thank you, Mr. Chairman, and thank you, Senator Harkin, as well.

I welcome Secretary Riley. It is always a pleasure to work with you on issues facing us in our schools across the country. I especially appreciate your support and help from the Department's level in our attempt to reduce class size.

FEDERAL EDUCATION FUNDS AS PERCENT OF TOTAL BUDGET

None of us want to pit special education students against other students in any way. And in setting priorities I think we set up false choices, if we try and do that. Certainly we have to get down to dollars and cents and how much we are going to allocate for each. I believe if we set our priority at the national level to fund education in a way that is adequate, much more than the 1.6 percent of the Federal Government's budget that we currently do, we can set priorities that benefit all children, all students, all communities and I hope that we can continue to work in that direction.

Mr. Secretary, you have done a great deal for students across our country in your tenure at the Department. I want to thank you not only for the education initiatives that you put out there, but for going out and coming to our schools, visiting the different sites, facing students and teachers and parents on an eye-to-eye level and really understanding what the needs are out there.

I know when you see what all of us do, when you visit our schools, that you see there are a lot of needs. I am often struck by the fact that people question whether there should be a Federal

role in education. And I would like to hear your opinion about this as well.

But it is my feeling that we absolutely have to have a Federal role. None of us can opt out of this. If you could respond in a general way as to how you see that, I would really appreciate it.

FEDERAL ROLE IN EDUCATION

Secretary RILEY. I have said before, Senator, that in my view, and, of course, I am a former governor, as is the President, that education is chiefly a State responsibility and a function then of the local schools and they, at the local school districts, are creatures of the State. And that the Federal Government in this education era—this information era—the Federal Government does have a very important role.

It is really, when you think about it, it would be kind of foolish for us to be in this enormous education era, and with this country being the leader in the world in so many ways, for us not to have a national purpose to have education be very important, a priority.

I think we can do that, and the way that we propose to do it is not to take control away from the States but to support things that are working in the States, things that we can clearly see that make a difference, a support system, a priority system for State and local governments.

CLASS SIZE REDUCTION

And in terms of class size that you have been such a leader in, it is very clear—you go from State to State, you talk to parents, you talk to anyone else—class size, especially in those early years or especially for reading, is always listed as a priority.

STAR STUDY

And it simply makes a big difference in so many ways, as you know. And it makes a difference as shown in these studies, very good studies of class size reduction, such as the Student-Teacher Achievement Ratio (STAR) study from Tennessee, for these children. The STAR study is a longitudinal study; they are tested again in the 8th grade and the 9th grade, and it showed it makes a difference by having a small class size in those early years.

So I think the Federal Government has a very legitimate role. We do not tell States who to hire as teachers. We do not set up how they should pick teachers or whatever. But we try to provide leadership and research information and so forth. But I think that is a very legitimate Federal role.

AUTHORIZATION OF CLASS SIZE REDUCTION INITIATIVE

Senator MURRAY. Thank you, Mr. Secretary, and I agree with you a hundred percent that our job is to support what is happening at the local and State levels and particularly in arenas that do make a difference, and reducing class size is clearly one that does.

As you mention, the STAR studies show that. And it is not just a one-time help. It helps all the way along. We want all of our kids to succeed. I will be offering, as you know, an amendment on the Floor of the Senate today regarding class size, authorizing the pro-

gram for the next 6 years. And the question always comes up, "Why do you have to do it today?"

Could you give me your perspective on why it is important for us to take this step now in terms of reducing class size?

Secretary RILEY. I think one of the important reasons is, of course, we funded the first year last year, and that money is just now—as you know we forward fund most of our education programs—and that money is just becoming available for the school year.

And it is very important for those school districts out there that are choosing teachers and are deciding how they are going to have qualified teachers in their classrooms to know that this is a program intended to be authorized and to be a permanent program.

If they do not, they have a terrible decision in deciding whether to hire these teachers that can lower the class size and make a big difference when they are afraid they might lose the funds if it is not authorized. So I think it makes an awful lot of sense now to say to the school people out there this program is authorized. It is something that we on the U.S. side, Federal side intend to support.

Senator MURRAY. I agree with you.

And as a former school board member, I know they are sitting there this month making decisions about their budgets for the following year and looking at programs and wondering was this just something you did last October. Is it something we can count on. And that will make a determination of what they do in terms of hiring decisions. They are beginning that process right now.

PREPARED STATEMENT

I appreciate your Department's support on this initiative, and we look forward to success. Again, thank you for all your work on behalf of education in this country.

Senator SPECTER. Thank you, Senator Murray.

[The statement follows:]

PREPARED STATEMENT OF SENATOR PATTY MURRAY

I want to thank Secretary Riley for his comments today and for his tremendous leadership. The children of this nation owe a great debt to Secretary Richard Riley, because all his vision, all his advocacy, all his hard work spurring national investment in education—he does it all to make sure today's children are tomorrow's successful adults and citizens.

The appropriations priorities that President Clinton has proposed this year continue a multi-year effort to improve federal funding for schools. The priorities within his proposal—improving the quality of America's teachers, helping communities to modernize facilities, investing in education technology, and especially, continuing efforts to help school districts hire 100,000 highly-qualified teachers—are priorities shared by many on this subcommittee and by the American people.

We can make no greater investment than in the time and attention our children get from their teachers, so it is vital that we continue to move forward on class size reduction, and fund the full $1.4 billion this year.

Of course, there are a few areas where I have specific concerns—the lack of a significant funding increase for IDEA has the effect of polarizing the education debate on Capitol Hill, and it does not help to get us to funding the 40 percent federal share of local school district cost. Impact Aid is another area where I strongly urge the President to do things differently next year.

But my larger issue, and I know Secretary Riley is supportive of my goals in this area—is the long-term look for overall education funding. Today, 1.6 percent of overall spending goes to education, and the American people think education is more than a 1.6 percent priority.

In a Greenberg-Quinlan survey in 1998, when asked whether the federal government is spending too much, too little, or the right amount on education, 58 percent of Americans said "too little," as opposed to only 9 percent who thought it was too much. People know that education is the most important investment we can make, and they know that despite all the gains we can get through increased efficiency and creative thinking—schools do cost money. They aren't afraid of wise spending on public education—they know that investment now heads off all kinds of costs down the road.

I want to work with Secretary Riley and the members of this subcommittee to see what we can do to make education funding more than a 1.6 percent priority in our appropriations process. Students are coming to the school house door with more costly needs every day—an investment to meet those needs now will strengthen our economy and national capacity for greatness in the future.

OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator SPECTER. Senator Cochran.

Senator COCHRAN. Mr. Chairman, thank you very much.

I join you and others in welcoming the Secretary to our hearing. It is always a pleasure to attend this hearing and review the budget request of the administration for the Department of Education.

TEACHER TRAINING—NATIONAL WRITING PROJECT

I am particularly pleased this year that there is an increase in funding requested for the National Writing Project. This is a teacher training program that has really proven to be one of the most successful teaching training models in the country. And it is gratifying to see the Department agree that it is a worthy program and justifies an increase in funding.

Coincidentally, I am introducing legislation today that will reauthorize this program and bring it up-to-date and to take into account the growth in the program. It now includes 156 sites in 46 States serving over 100,000 teachers at a bargain price.

TEACHER TRAINING—PBS MATH/LINE PROGRAM

In passing let me suggest another teacher training program that is proving to be very helpful as well and that is Math/Line. It is a PBS program, that has proven to be very effective in reaching large numbers of teachers. As a matter of fact, these two teacher training programs have the potential of reaching all teachers throughout the country, and I suggest we explore ways to see that that happens, that that becomes a reality.

ESEA REAUTHORIZATION

One other observation is about your observation on the Elementary and Secondary Education Act, that is not really under this budget right now, or this budget does not deal with that. But I am hopeful that as we approach the reauthorization of ESEA we make an extra effort to be sure that the Title I formula takes into account the impact of chronic poverty in States like Mississippi and there are others, not just singling out our State.

The Mississippi Delta region particularly needs special attention, and this program gives it that kind of special attention, but not if the formula tries to be everything to everybody, which has been the tendency in recent years. So I challenge the Department to look for ways to make sure that the Title I formula is equitable and recog-

nizes the stress that school districts have in areas of chronic poverty.

I suppose you can tell from my statement that I do not really have any questions. I have some opinions and I thought I would just express them. But we appreciate the opportunity of working with you, Mr. Secretary. Any reaction you would like to give to those observations, I would be happy to hear, though. And I ask that all of my remarks be printed.

Senator SPECTER. Without objection, the full statement will be made a part of the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR THAD COCHRAN

I will introduce the National Writing Project amendments and reauthorization bill this day at 12:45 p.m. The National Writing Project began as the only Federal program to support the teaching of writing in fiscal year 1991. The fiscal year 1991 appropriation was $2 million. The administration included funding in its budget request for the first time last year, a level funding of $5 million. Congress, at my suggestion, increased the funding to $7 million.

This year, the Department of Education requests $10 million for fiscal year 2000. And, it has made the National Writing Project a major stone in its education plan. It's about time.

The amendments will expand and update the authorizing legislation under the Elementary and Secondary Education Act to reflect the growth of the National Writing Project. With 156 sites in 46 states, the Writing Project serves over 100,000 teachers every year.

It is a teacher training model, generates more than six times the relatively small federal investment. Teachers of all subjects benefit from training, and the success of students who are taught by Writing Project teachers is evident: they score better not just on writing examinations, but in reading and mathematics.

I hope the Department of Education will use the National Writing Project model as the model for the many teacher training proposals it has throughout its fiscal year 2000 request. The National Writing Project along with the highly successful MATHLINE, a PBS mathematics teacher training program, provide the potential to reach every teacher in the United States with effective training methods, at a bargain price.

I am disappointed in the funding requested for MATHLINE and Ready to Learn Television. These are important learning and teaching projects that reach thousands of teachers, parents, preschoolers and students. I hope we can increase those funds.

Title I funding for the education of disadvantaged children is always a concern to me. Again, it doesn't seem to matter how much money we put in this program, our struggle seems to be keeping Mississippi's share. I understand the problems with rises of poverty in other areas of the country, but I hope that this year we can establish a formula that recognizes the great impact of chronic poverty in states like Mississippi, and that assistance to other states is not at the cost of the children in the Mississippi Delta.

The Title I funds are the lifeline for most of the schools in my state. Principals tell me every year about the tremendous improvements they have been able to make school wide.

I question the advisability of the high spending level for reading improvement, not because I don't believe we need improvements, but because of the frustration that still exists by administrators and principals in being able to choose reliable materials and training to actually do some good. The National Institute for Child Health and Human Development, for instance, has conducted research, at Congress's request, that produced a screening method that can be implemented for less than $20 per child. That's a first step. One that, it seems to me, would be money well spent.

The National Reading Panel has recently sent to me a progress report on their work. This panel was created as a result of legislation I introduced in 1997. The Panel traveled the country and, "heard from 44 invited presenters and 73 members of the public who addressed their concerns about reading."

In the report, the panel sets out the scientific methodology by which reading research ought to be judged. It took this panel of distinguished researchers, teachers, administrators and informed parents, nearly a year to get to this point. It is not

a rushed process. I'm encouraged by their work and think we will have good advice when they are finished, projected to be in early 2000.

I hope the Department will use this information and move cautiously before encouraging school districts to spend hundreds of millions of dollars on unproven methods, which according to this report, may actually impede the progress of students learning to read.

I ask that the report be included in today's hearing record.

I continue to be concerned about the trend in Foreign Language assistance; that is, that over the last five to 10 years, there has been a decrease in the funding for the small program to help schools develop foreign language classes. Currently, the program is $6 million for matching grants to school systems. I hope we can work on improving not only the funding level, but the distribution of those funds.

[CLERK'S NOTE.—The report referred to in Senator Cochran's statement does not appear in the hearing record, but is available for review in the subcommittee files.]

NATIONAL WRITING PROJECT

Secretary RILEY. Thank you, Senator.

I would say this. You have provided grand leadership in the area of writing, preparing teachers to help them teach better in this writing field. And your involvement has certainly had an impact on our thinking about it. And we did request in this budget an increase of $7 million to $14 million for the year 2000.

And I really do think that is very important—it is not a giant thing but, as you point out, it impacts a lot of teachers. And a lot of young people nowadays with computers and other things do not write like they used to, and even writing on the computer is important. But I think that is a very outstanding thing for you to have pressed for in the past and it is making a difference.

I agree with you on the Math Line. That is a very impressive teacher aid. Math teaching is so important. And a lot of teachers will say that math is an area that they need special help in and this is a very good program.

So I thank you very much for your statements.

Senator SPECTER. Thank you, Senator Cochran. Senator Harkin?

Senator HARKIN. Thank you, Mr. Chairman.

TRIO PROGRAMS

Mr. Secretary, one of the programs that I have been involved in for a long time, I have watched it from both the authorizing end and the appropriations end, and that has been the TRIO program, 30-year record in the TRIO program.

Now I do not know, but from all that I have seen in the past of sitting in the chair that now is occupied by my friend from Pennsylvania and sitting on the authorizing committee, it has been a very successful program.

I have met a lot of people who have been through that program and minority students, disadvantaged students who came through the Upward Bound or the Talent Search Program. And I guess what I am wondering is this. We have a Talent Search Program that serves 320,500 students with $100 million. The GEAR UP Program is proposing $250 million, 2½ times as much, to serve 381,000 students, about the same.

I am wondering what is going on there. Why can we not just use the Talent Search program?

Secretary RILEY. I think both programs are very important. I do not have to tell you, Senator, because you clearly understand this. It is about getting young children prepared for college, children who otherwise would not have considered preparing for college—children who thought college was for somebody else. And we have got to get over that hump.

The TRIO program has done a wonderful job of doing that. It does have a program that reaches to individuals in those early years primarily in high school and college.

Senator HARKIN. High school.

Secretary RILEY. Yes. And it helps kids through college in another program.

GEAR UP AND TALENT SEARCH PROGRAMS

What GEAR UP does is in the same area, but it is different. It connects up schools. It connects up very poor middle schools, for example, with colleges and with other community-based groups. In this connection the entire school is then impacted through this linkage with higher education. And then they help these kids, monitor them and tutor them on through high school and whatever. So I think it is——

Senator HARKIN. Are you describing the Talent Search Program?

Secretary RILEY. Talent Search is an individual program that deals with individuals. This is a school program. GEAR UP is a school program that——

Senator HARKIN. I thought GEAR UP was for mentoring, tutoring, that type of thing.

Secretary RILEY. It is. Structurally it connects up schools to colleges and then the other part of it is a State program. So they are different programs.

This really looks at a higher concentration of poverty area middle schools—Berkeley, is an example. The Berkeley Pledge Program that was done out there. It is such an effective program to have a fine university like U.C. Berkeley connect up with two or three middle schools, and I mean the entire schools, and to have these college students working in these schools and professors back and forth and then identifying problems for children and working them through.

Senator HARKIN. So the difference is the Talent Search Program is individually targeted, but the GEAR UP program involves connecting a school to a college.

Secretary RILEY. That is one big difference. And the other one is GEAR UP is primarily focused on middle school and while some of the TRIO program reaches middle school.

Senator HARKIN. It sure does.

Secretary RILEY. But that is not a priority. Well, it is a priority, but the larger part is focused on high school.

Senator HARKIN. Mr. Secretary, I appreciate it. I have just always had a hard time understanding this GEAR UP program and why we could not have just used the existing structure of the TRIO program and the Talent Search Program to accomplish the same thing, but I intend to look into that further.

95 PERCENT TO THE CLASSROOM

My time is limited. I just have one other point I want to cover with you, Mr. Secretary. A recent statement was just made on the Senate floor and I will read it to you. I will not name the Senator, but a statement was said about this ED–FLEX bill. It said it would allow new flexibility to State governments in ensuring that 95 cents of every dollar gets to the classroom as opposed to the 65 cents that currently get there.

What I want to know is if you can help set the record straight here and see how much is eaten up by administrative costs. Is it really 65 cents that gets out there?

Secretary RILEY. And that has disturbed me quite a bit to see some of these references as to how the Federal Government is eating up all this money. I appreciate the question.

If you look at the Federal administrative costs of the Federal Government—our costs in the Department of Education—it is the smallest Department, I think, in the Federal Government, with 5,000 employees. As you know, we have come down from 7,000 since we became a Department. For elementary and secondary programs, the Department of Education Federal administrative cost equivalent is around one half of 1 percent. The State cost then, the State administrative cost of State formula programs—and there is a reason that there is more State administrative cost—is around 4 percent. So as far as what gets to the school district in the schools out here with Federal programs, it is like 95.5 percent of the money. And when people say this enormous sum of 30 and 40 percent is taken out by the Federal Government to administer these programs, it really is misleading.

SEPARATE APPROPRIATION FOR DEPARTMENT ADMINISTRATION

Senator HARKIN. I wonder where that 65 percent figure comes from. Let us just say that when we appropriate money for a program such as Title I or even a smaller program like the National Writing Program or STAR schools, does the Department take a cut off the top for administration of those programs?

Secretary RILEY. Well, the Department's administration money comes from a separate appropriation for salaries and expenses. That is why I say the Federal equivalent is like one half of 1 percent.

Senator HARKIN. So when we appropriate money on this committee for a program, there is not a certain amount of that taken out for administration?

Secretary RILEY. No, sir.

Senator HARKIN. That money comes in a separate appropriation for salaries and expenses; is that correct?

Secretary RILEY. Yes; and that is why our program administration cost is equivalent to about ½ of 1 percent.

Senator HARKIN. And then you say about 4 to 4½ percent is retained by the State?

Secretary RILEY. Yes, sir; but for Title I the law provides the State cannot take out more than 1½ percent. So for Title I, 98½ percent of the money—98½ percent of the appropriated money gets to the local school district.

Senator HARKIN. So you are saying, again I just want to make the record straight, you are saying that with the exception of Title I, which has a 1½-percent limit for administration on the State side, you are saying that 95½ percent of the funds that we appropriate here get to the local school district.

Secretary RILEY. That is right.

Senator HARKIN. How much actually gets to the classroom? Do we know that? Do we have any idea of who actually gets——

Secretary RILEY. Well, there are ways to determine that. It varies, of course, significantly from school district to school district, and those are important issues.

But, of course, you have elected school board members that make those decisions. And it has always been my judgment that we in the offices up here in Washington ought not to be involved in what the local school district does. Some of them might spend too much money in the eyes of people. Some of them might spend too little money. But the important thing is what gets to, in my judgment, what gets to the local school district.

Senator HARKIN. I appreciate your setting the record straight.

I was in my home State here just 1 week ago, 2 weeks ago and this came up about all of this money being used, taken out of education, and the 65-percent figure is somehow rolling around out there. I do not know from whence it came. I am glad you set the record straight on that.

Secretary RILEY. Thank you.

Senator HARKIN. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Harkin. Senator Gregg? Senator Kohl?

PREPARED STATEMENT

Senator KOHL. Thank you. Thank you, Senator Gregg.

I ask that my prepared statement be inserted into the record at this point.

Senator SPECTER. Your prepared statement will be inserted into the record as requested.

[The statement follows:]

PREPARED STATEMENT OF SENATOR HERB KOHL

Thank you, Mr. Chairman. And I want to thank you, Secretary Riley, for appearing before this Subcommittee today to discuss the fiscal year 2000 budget for the Department of Education.

I am pleased to see that the President's budget request again includes an increase for the Department of Education. However, I am concerned that the increase is only a modest one—only 3.7 percent—when our need to improve education is so great.

The Federal government's role in education is to be a wise and generous investor in a public education system run by State and local governments. We need to be generous because the investment is directly in our future—in the children who will determine whether this nation remains economically strong, intellectually rich, and socially just. We need to be wise because we in Washington simply do not know what will work for the children of Wauwatosa, Wisconsin or Wichita, Kansas. Our educational needs are as diverse as our population.

And States and communities are rising to the challenges of educational reform. For example, Wisconsin's SAGE program has been extremely successful in reducing class size and improving learning in the early grades. Milwaukee's Teacher Mentoring and TEAM programs are both improving the quality of teaching and encouraging teachers to stick with teaching. And many Wisconsin communities are working to bring more people from diverse backgrounds into teaching.

When we give communities the resources and freedom to care for their children, they do. And, unfortunately, when we try to do it for them from inside the beltway, we often make ridiculous mistakes. I will be talking to you, Secretary Riley, about one of these later: a glitch in the class size reduction initiative that would have rural teachers racing between school districts rather than running classrooms.

I thank you again, Secretary Riley, for appearing before the Subcommittee today. I look forward to discussing the President's budget in more detail, as well as your comments on programs that support quality teaching.

CLASS SIZE REDUCTION—ALLOCATION FLEXIBILITY

Senator KOHL. Secretary Riley, I would like to ask a question about the legislation surrounding 100,000 teachers which I support, but there is a quirk in that legislation that maybe you can offer a fix for. The legislation says that if a school district does not receive enough money to hire a full-time teacher, then that district must form a consortium with another district or several other districts to be able to afford to hire a full-time teacher and then share that teacher between the several districts.

In rural areas of my State and other States the districts are so large that the teacher winds up spending the majority of his or her time on the road simply trying to get from one school to another. I am sure you did not intend for this to occur. And I understand there has been some discussion about fixing it so that we can, in fact, allocate that money in a way so that it can be used for the purposes intended to be used for and not just for travel.

Can you give a response to that problem?

Secretary RILEY. Yes. And I appreciate, Senator, you bringing that up and your staff has brought it up with my staff and it is a very real observation that is out there.

In these rural school districts you do need a certain kind of flexibility to make it work well. We think we have that flexibility now and we are working on that. And we will respond. And if something further is needed in terms of legislative changes, we will let you know. But we think that we can work that problem out within the flexibility that is now provided.

Senator KOHL. OK. Is it possible then to see to it that we get that fixed for the money that was appropriated last year, so that rural school districts do not lose that money?

Secretary RILEY. Yes, sir. Of course, that money is forward funded. That money has not gone out yet.

MENTORING PROGRAMS FOR NEW TEACHERS

Senator KOHL. OK. I would like to discuss for just a moment the mentoring programs around our country. We have a mentoring program in the Milwaukee public schools. Last year we hired 1,000 new teachers and they afforded mentoring to 180 teachers. There is a substantial increase in the retention rate for teachers who participate in mentoring programs.

I think they have been demonstrated to be useful and effective in that they work and that they are cost-effective. How do you feel about mentoring programs, Mr. Secretary, and is there some way that the Federal Government can be more active in providing funds for mentoring programs?

READING MENTORING PROGRAMS

Secretary RILEY. Well, yes, I think so. The Reading Excellence Act, the America Reads Challenge that we have out there involves mentoring and tutoring and several other programs. College Work-Study is related to that. In those College Work-Study programs we worked out an incentive for college students to serve as reading mentors for children who need special help.

And we have over a 1,000 colleges—1,200 colleges and universities—that are involved in that program. We definitely will work closely with mentoring programs in your State as we do in Houston and L.A. and New York and all around the country to help train individuals—older citizens in many cases and often in some cases peer-aged children, to serve as mentors and tutors for children. But our reading priority will go a long way in serving that purpose.

MENTORING PROGRAMS FOR NEW TEACHERS

Senator KOHL. OK. I was referring in this discussion particularly to mentoring activities for new teachers.

Secretary RILEY. Oh, for teachers.

Senator KOHL. So that we can increase our rate of retention, mentoring activities for teachers.

Secretary RILEY. Title II that was reauthorized last year, of course, under the Higher Education Act reauthorization that you all dealt with last year, Title II of that deals with teacher recruitment, teacher preparation and teachers in general. And it can deal with mentoring—to what degree, Mr. Smith?

ESEA REAUTHORIZATION TEACHER MENTORING PROVISIONS

Mr. SMITH. It can deal with it to some degree. But there is a new provision that the Secretary talked about when he testified about the new Elementary and Secondary Education Act proposal which would emphasize teacher professional development.

And a major part of that emphasis would be on mentoring, taking those teachers who are coming for the first 3 years, assigning them a very highly qualified teacher to work with them and other teachers to observe them and so on to give them feedback. And I think that kind of thing, Senator, is exactly right.

Senator KOHL. So you are intending to do that?

Mr. SMITH. Yes.

Senator KOHL. I thank you. And I thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Kohl. Senator Gregg?

SPECIAL EDUCATION BUDGET

Senator GREGG. Mr. Secretary, I want to follow up on the Chairman's discussion with you about special ed because I, for one, do not understand the antagonism that this administration has toward the special ed program.

In the budget, I put up a chart up there, that you put forward you propose $1.2 billion in new spending. Of that $1.2 billion only $3.3 million goes to the special ed program.

FEDERAL SHARE OF EXCESS COSTS TO EDUCATE DISABLED

The problem with this is significant in that the Federal Government made a commitment to fund 40 percent of special ed. As a result of the leadership of this committee, Senator Specter, we have gone from a 6-percent commitment—fulfillment of that commitment up to about 11 percent now. So we are now funding 11 percent over the last 3 years.

The administration during that period has proposed no significant increases in special ed in any of its budgets. But when you come forward today and you propose a $1.2 billion increase in educational funding, you are essentially borrowing that from special ed obligations the Federal Government has and using it to initiate new categorical programs on the local States and communities which will require them to undertake what you decide is appropriate versus what the local communities decide they need to have done.

Or to put it another way, when a local community has to pay the Federal share of special ed, which is what it is having to do today because the Federal Government refuses to pay the 40 percent—it is only paying 11 percent—when the local community has to pick up that 30 percent that should have been paid by the Federal Government, it is taking local resources and having to allocate them to a Federal obligation set out by the Federal Government. So the local community cannot make a decision with its local dollars to hire a new teacher or to create an after-school program because it has to use its local dollars to fund the special ed funds which the Federal Government was supposed to fund in the first place.

So when you expand Federal education funding at the Federal level and you do not use those new expanded funds to fund special ed, you are further aggravating the local community's inability to make its own decisions as to how it should educate its children with its dollars. You are borrowing from their special ed dollars which they should be getting from the Federal Government in order to finance your now expanded programs.

SPECIAL ED FORWARD FUNDING PROPOSAL

In addition, not only does this budget not have any significant increase in special ed and does not make any effort at all to meet the 40 percent obligation the Federal Government has, but you have forward funded $2 billion of special ed money in this budget. So you have played a game with the special ed kids. You have taken $2 billion out of their account, pushed it into next year and then spent that $2 billion on some other initiatives, whatever they happen to be, putting the chairman of this committee in an almost untenable position.

This, to me, has been the most egregious education activity of this administration. For an administration which claims to be an education administration to really treat the special ed program as a stepchild and to fund it in this manner, not fund it at all essentially, is a reflection to me that the administration is not so interested in its obligation as a Federal Government, but is rather interested in creating new programmatic activity which will make the Federal Government even more intrusive into local education.

That is a statement, obviously, and we have discussed this before. But it is a statement based on some numbers that support it. I guess my question goes back to what the chairman said. Why does this administration continue to abandon the obligation it has to fund special ed in order to create new programs which are not necessarily needed by the local communities, but even if they are needed by the local community, could be funded by the local communities if the Federal Government fulfilled its obligation to fund special ed.

RESPONSIBILITY FOR FUNDING SPECIAL ED

Secretary RILEY. Let me speak to the issue of whose responsibility it is to fund education for disabled children.

The fact is, that is a responsibility of the State. State constitutions, general laws of the State say that the State will provide free public education for all children in the State. Of course——

Senator GREGG. Is it your position that through Public Law 94–142, that was passed in 1975, the Federal Government made a commitment to fund 40 percent of the educational costs?

Secretary RILEY. There is no question that the authorization is up to 40 percent of the educational costs and that statement was made and people anticipate that it is something that we would reach for. No question about that.

I wish we were there. If we were there, it would cost an additional $11 billion a year.

Senator GREGG. Which is essentially the cost of your new initiatives when they are put on the books for a year.

Secretary RILEY. Well then if it is a State responsibility, the Federal Government comes in and says you do not have to take IDEA. That is not a mandate. States do not have to accept IDEA. But if they do, then they have to comply with IDEA.

The anticipation hopefully would move closer in the direction of the 40 percent. But it is not a mandate for the Federal Government to pay 40 percent. So this is what I am saying. Every State takes IDEA because it involves a lot of money.

The current language in IDEA says that if you exceed $4.1 billion, then I think 20 percent of the increased money can be used for local government. However, they want to use it not even for education purposes. So you have got now local government resources being increased by IDEA, that is not directed necessarily to help disabled children.

As I indicated earlier—I am not sure whether you were here—if the caps were not there and there was money for an increase, I would certainly favor IDEA and Pell grants and things of that kind, teacher quality——

Senator GREGG. If the caps are not there, then you are going to take it out of Social Security. Is it your suggestion that we should be funding the new teacher programs from Social Security?

Secretary RILEY. No; we have submitted in our budget what we think is a way to allocate—our recommendation for allocating the funds. We have $116 million in there for IDEA, for disabled children. A good part of that is for prevention of problems and then we have a significant amount of money in there to deal with the regular classroom.

Some 75 percent of disabled children are in regular classrooms over 40 percent of the time. So it affects everybody to have smaller class sizes, especially for those young years, and to have school construction and teacher quality and after-school programs and so forth.

So we think all of those programs work together. It is not just a fixed view on one thing, but it is all related. And I strongly support doing as much as we can in a sensible way to help disabled children.

Senator GREGG. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Gregg.

CHARTER SCHOOLS

Mr. Secretary, thank you very much for coming today. I just have one minor question. Yesterday the Philadelphia City Council took up the issue of charter schools with the issue turning on some 12 additional charter schools over and above the 15 which are now authorized—13 being in existence, two additional schools to currently be authorized.

The total cost is $40 million for the 27 charter schools and the superintendent of schools, Mr. Hornbeck, expressed the view that the money could be better spent on the $94 million shortfall in the city of Philadelphia. Of course, their problems are exactly the same as our problems. It is a limited number of dollars and there are competing interests.

I always felt the charter schools constituted a good idea—keeping it within the public school system, the issue of vouchers and separate school system, along with privatization—is a good experiment to provide competition for the public schools. And now we are looking at a stark situation in my hometown—a $94 million shortfall, $40 million for charter schools. And I would be interested in your appraisal, if you care to give one, as to how you would assess this priority choice.

Secretary RILEY. Well, Mr. Chairman, I think it would be a real mistake to get into local decisionmaking.

Senator SPECTER. It is part of the United States.

Secretary RILEY. It is part of the United States.

Senator SPECTER. I understand your jurisdiction.

Secretary RILEY. It is a local shortfall and it is a problem and then the question, of course, is how does a new charter school program weigh against a current shortfall. I really would be reluctant to express my view on that because I do not know all the details and the facts and the history.

But I would say this. I agree with you that charter schools are a very good alternative for school boards to have. Of course, they depend on the State law and they depend on funding and so forth. But as you know, we have requested a $30 million increase this year from $100 million to $130 million which shows our support for the concept.

Charter schools are a wonderful alternative. It is a wonderful option for school districts to have and it can be, I think, a good part of the mix. So I would say that this school superintendent and others would have to weigh those factors with their local problems and decide what they think is best for the district.

Senator SPECTER. Thank you very much. We will not be including a line item to relieve them of the necessity of making their choice in Philadelphia.

ADDITIONAL COMMITTEE QUESTIONS

There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

SPECIAL EDUCATION—GRANTS TO STATES BUDGET REQUEST

Question. The $4.3 billion appropriation in fiscal year 1999 represents only 10 percent of the 40 percent goal the Federal Government intends to provide to meet the excess cost of educating children with disabilities. If the 40 percent goal were to be met, it would cost the Federal Government an additional $11 billion over the current appropriation or $15.3 billion. The fiscal year 2000 budget request for Special Education Grants to States is level-funded at the fiscal year 1999 appropriation of $4.3 billion.

Why is the Administration requesting level funding for this program when we are so far away from reaching the 40 percent mark?

Answer. While no additional funds are requested for the Special Education Grants to States program, our request includes $4.3 billion for funding this program. Since fiscal year 1996, funding for Grants to States has increased by almost $2 billion, or 85 percent. We believe that the current level of funding provides an appropriate level of support given the fact that States have the primary responsibility for educating all children, including children with disabilities.

Special education programs with funding increases

The Grants to States program is sometimes viewed as the Federal program for providing assistance to States in serving children with disabilities. Additional funds are requested for other Special Education programs that will help States serve children with disabilities. These include increases of $20 million for Grants for Infants and Families to help States provide early intervention services for children with disabilities from birth through age 2 and their families, $28 million for Preschool Grants to help States provide special education services for children aged 3 through 5 with disabilities, and $10 million for State Improvement grants to help States reform and improve their educational, early intervention, and transitional services systems. An additional $50 million is also requested for new Primary Education Intervention grants to local educational agencies to help them improve results for young children with disabilities.

Other education programs addressing the needs of children with disabilities

Children with disabilities also benefit from other Federal education programs that are not focused solely on children with disabilities. These programs include programs such as the Class Size Reduction Program that helps schools hire highly qualified teachers and reduce class size; Eisenhower Professional Development State Grants that help ensure that teachers, including teachers of children with disabilities, have the content knowledge to help children achieve to high standards; and 21st Century Community Learning Centers that provide a safe environment and expand learning opportunities for children before and after school. Federal subsidies for school construction bonds that will be used to repair, renovate, and construct schools will help ensure that our school buildings enhance the teaching and learning of all children, including children with disabilities. We believe that our request reflects the best combination of programs and funding to address the needs of all children.

CLASS SIZE REDUCTION FUNDS MATCHING REQUIREMENT

Question. The fiscal year 2000 request is for $1.4 billion and with a new requirement for local school districts to match up to 35 percent of any funds they receive above the $1.2 billion appropriated in fiscal year 1999. An exemption would be made for any district with at least 50 percent of its students from low-income households.

If the very purpose of the program is to help disadvantaged school districts who are struggling to resolve the overcrowding issue, how do you expect these schools to meet the 35 percent matching requirement?

Answer. The Department does not believe that requiring local districts to provide a 35 percent match on any new Class Size Reduction funds they receive would be burdensome for most districts, and those districts that would have the greatest difficulty in providing such a match would be exempt from the requirement.

For an average district, the amount of the match would be only about $7,200. The Department estimates that approximately two-thirds of all districts would have a matching requirement of no more than $2,700.

Further, research has demonstrated the benefits of reducing class size in the early elementary grades, particularly for lower-achieving, minority, low-income, and inner-city students. The Department believes districts welcome Federal support to help them reduce class size in the early grades.

MATCHING REQUIREMENT EXEMPTION PROVISION

Question. How is the exemption you propose feasible when class size reduction funds are provided to school districts with large proportions of low-income students?

Answer. All schools districts, not just those with large proportions of low-income students, are eligible to receive Class Size Reduction funds. We are proposing to exempt only those districts in which at least 50 percent of the students they serve are from low-income households. We estimate that, after exempting the highest-poverty districts, the average national match provided by local districts would equal 30 percent of the Federal appropriation.

ESEA REAUTHORIZATION—PROGRAM CONSOLIDATION PROPOSAL

Question. At a recent hearing held by the Senate Health, Education, Labor, and Pensions Committee, Secretary Riley proposed to consolidate the $491 million Goals 2000 program, the $375 million Innovative Strategies State Grants program, and the $335 million Eisenhower Professional Development program into one large "teacher training and improvement program."

Please explain your rationale for this proposal?

Answer. With Federal support and assistance, 48 States have implemented challenging academic standards and States continue their efforts to develop student performance standards and assessments aligned with their standards. There is strong evidence that those States that have led the way in adopting standards-based reform have already begun to see significant improvements in student achievement.

Consolidation proposal focus on professional development activities

The next challenge is to support teachers as they strive to make high standards a reality in every classroom. The Administration's proposal for reauthorization would build upon the efforts that States and districts have undertaken with support from the Goals 2000 and Eisenhower Professional Development programs to implement standards-based reform and improve the knowledge and skills of America's teachers.

Research has shown that qualified teachers are the most important in-school factor in improving student achievement. The Administration's proposal to consolidate the Goals 2000, Eisenhower State Grants, and Title VI programs would strengthen the focus of States and districts on providing the types of professional development activities that have been proven effective in providing teachers with the knowledge and skills necessary to prepare all students to achieve to challenging standards.

INNOVATIVE EDUCATION STRATEGIES STATE GRANTS PROGRAM

Question. Why not consolidate all of the funds into the Innovative Strategies State Grant program, which provides funds to States for whatever the particular need of the school district, and allow the schools to choose how best to spend these funds?

Answer. The Administration does not believe that Title VI, the Innovative Education Strategies State Grants program, is designed to support the types of State and local efforts most likely to result in real improvements in teaching and learning. The most recent evaluation of the former Chapter 2 program found that funds were used by fewer than half of the States to support such reform activities as revising/developing standards for student performance or developing alternative measures of student achievement. Individual districts were even less likely than States to use Chapter 2 funds to support educational reform efforts. The same evaluation also found that some activities supported with program funds had little direct impact, or no impact, on students, instruction, or school staff.

The Administration's reauthorization proposal would provide States and local school districts with flexibility in the use of funds, but would make the critical link between expenditures and standards-based educational reform that Title VI does not. The proposed program would support the efforts of States and local school districts to develop rigorous academic standards and to improve classroom practice and curriculum to help all students to meet those standards.

COLLEGE COMPLETION CHALLENGE GRANTS COMPARED TO THE STUDENT SUPPORT SERVICES PROGRAM

Question. The fiscal year 2000 budget request proposes a separate and new program, College Completion Challenge Grants, with $35 million in funding to support activities to help at-risk students complete college. The existing TRIO Student Support Services program has much of the same focus by providing remediation, counseling, tutoring, among other services to low-income college students, whose parents have not completed a bachelors degree, and to disabled students to enter and complete college.

How would the College Completion Challenge Grants you are proposing for the fiscal year 2000 budget differ from the kinds of services that are already being supported under the Student Support Services program, one of the Federal TRIO programs?

Answer. The College Completion Challenge Grants program, newly proposed in fiscal year 2000 for $35 million, would be different from the Student Support Services program of TRIO in that it: (1) would focus solely on students in their first years of postsecondary education at risk of dropping out and; (2) would provide increased student-aid grants. While the Student Support Services program has proven to have a strong impact, this new program would complement these efforts by targeting at-risk students in their first years and providing them with more grant aid than they would normally receive—a feature TRIO does not offer. Furthermore, it would also help colleges provide intensive summer programs to increase the level of academic and social involvement of first-year students.

GEAR UP INITIATIVE COMPARED TO COLLEGE COMPLETION CHALLENGE GRANTS

Question. How would this program differ from another college preparation and awareness program, GEAR UP, which is proposed to receive $240 million in fiscal year 2000?

Answer. The GEAR UP program is very different because it targets middle school students, helping them to get into college. In contrast, the College Completion Challenge Grants program would provide an innovative approach to college retention for students who are already in college. In this way, these programs would not duplicate each other, but would be complementary; they would join efforts, College Completion Challenge Grants picking up where GEAR UP stops, to help ensure that middle school students enter and complete college.

PROS AND CONS OF CONSOLIDATING COLLEGE PREPARATION PROGRAMS

Question. In your opinion, what are the pros and cons of consolidating all of these college preparation programs?

Answer. The problems of college access and attrition are so serious and complex that successfully increasing student enrollment and retention throughout the Nation will require a multi-faceted approach. While it would be possible to consolidate these programs and thereby reduce the statistical number of programs, successfully doing so would require creating one, extremely large program with many sub-programs. The problem with such a consolidation is that each of the higher education programs has different target populations and approaches.

The goal of GEAR UP is to start middle school students on an academic pipeline that propels them into college. On the other hand, the goal of the College Completion Challenge Grants program would be to help institutions of higher education focus more resources on at-risk college students to ensure they graduate. As you know, TRIO already consists of five, highly important but separate programs. Each of these utilizes different approaches and focuses on different population groups. Therefore, attempting to create a single, efficient, and yet wide-reaching program with such a detailed and goal-oriented focus would be virtually impossible. The most efficient and effective way to solve the problems of college access and attrition is through several, comprehensive and focused programs like we propose, programs that complement each other with different approaches.

QUESTIONS SUBMITTED BY SENATOR TED STEVENS

SPECIAL EDUCATION ALASKA PILOT PROJECT

Question. Last November, I held an education conference with the Alaska Commissioner of Education, the head of the PTA and Parents, Inc., school district officials, and top educators to discuss the state of education in Alaska. I'd like to raise a couple of issues that came out of that meeting. Alaska has the highest rate of fetal alcohol syndrome in the Nation, and as a result, one of the fastest growing rates of children requiring special education. In fact the Anchorage School District estimates that 25 percent of its students currently are enrolled in special education classes, and they project that figure will grow to one-third just after the turn of the century. So there is tremendous demand for special education programs in our State.

But across the board, there is great dissatisfaction with existing special education programs. Parents feel that it is too bureaucratic and that resources go into paperwork and not into improving their children's educational achievement. Teachers believe mainstreaming children with serious behavioral problems creates huge discipline problems in the classroom. Administrators who are forced to hire teacher's aides, in some cases for each special education student, complain that the system is too costly. But everyone remains committed to provide the very best education possible for children with disabilities and learning problems.

I asked the commissioner to convene a task force to develop a statewide pilot project for Alaska, which could cut through some of the red tape and focus resources where they are needed—on the children. The group includes parents of disabled children, teachers, administrators, and even students. They have nearly completed their work and are almost ready to present their plans.

Would you be willing to work with us to develop and implement this effort through the special education innovative research program?

Answer. The Department has several resources that are available to Alaska in pursuing reforms. In particular, our Office of Special Education and Rehabilitative Services is committed to a policy of continuous improvement through working with States. The Regional Resource Centers (RRCs) funded through our Special Education Technical Assistance and Dissemination program work with States to develop individualized technical assistance plans to support States in their efforts to improve services and results for children with disabilities. The Western RRC, which serves Alaska, is located at the University of Oregon in Salem. Other Special Education technical assistance and information resources address specific State concerns ranging from financing services and testing to grade specific services for children from preschool through secondary school.

Staff in the Office of Special Education and Rehabilitative Services are also available to work, in collaboration with technical assistance and information providers, to assist Alaska. We believe that these staff would be particularly useful in helping the State to identify paperwork, policies, and procedures that may be unnecessary to meet Individuals with Disabilities Education Act requirements.

I should also note that Alaska is eligible to apply for funds under the State Improvement grants program. This program, which was authorized by Congress in the Individuals with Disabilities Education Act Amendments of 1997, provides competitive grants to State educational agencies to assist them and their partners in reforming and improving their systems for providing special education, early intervention, and transitional services to improve results for children with disabilities. This program, rather than the Research and Innovation program, which focuses on producing and advancing the use of knowledge, would be the most appropriate source of support for implementing Alaskan reform initiatives.

DISTANCE LEARNING

Question. During recent meetings with Alaska's health care providers, I learned that there were numerous competing tele-health initiatives in the State. I told them all that Federal funding for all of these projects would be impossible unless they coordinated their efforts. I was concerned that they were duplicating efforts instead of complementing each other's services. $100,000 was provided to develop a statewide tele-health plan, and that effort is now underway.

Upon further investigation, I am learning that the same problem exists within tele-education. Various school districts have a tele-education plan. Public broadcasting is involved with different stations on various projects. Further, different campus sites within the University of Alaska even have competing programs. I would like to convene a similar task force for distance learning and get everyone to work together to develop a statewide plan.

Please advise me of your distance learning grant programs that could be applied to begin the effort.

Answer. The Department's primary sources of support for distance learning projects are the Star Schools and Learning Anytime Anywhere Partnerships programs. The Star Schools program supports projects that provide instructional course content for students and professional development activities for teachers through distance learning technology. The Learning Anytime Anywhere Partnerships program supports pilot projects using technology and other innovations to enhance the delivery of postsecondary education and lifelong learning opportunities for all citizens, in a variety of settings.

In addition, grantees receiving funding under the Department's Technology Innovation Challenge Grants program can use those funds for distance learning activities. The Technology Innovation Challenge Grants program provides competitive 5-year awards to consortia that include at least one local educational agency with a high percentage of children living in poverty. Consortium members may also include other local educational agencies, State educational agencies, institutions of higher education, businesses, museums, libraries, academic content experts, software designers, and others. Also, local districts receiving competitive awards under the Technology Literacy Challenge Grants program can use those funds for distance learning activities.

Distance learning—learning anytime anywhere partnerships

Our new program, Learning Anytime Anywhere Partnerships (LAAP) was funded for $10 million in fiscal year 1999. LAAP provides grants for up to 5 years to support pilot projects using technology and other innovations to enhance the delivery of postsecondary education and lifelong learning opportunities in all settings. The program requires partnerships including educational institutions, State and local governments, community organizations, and others. Application packages became available on January 26, 1999, and completed pre-applications are due by April 2, 1999. The Department anticipates making 25–30 awards up to $500,000 each.

Distance learning—star schools

The Star Schools program utilizes distance education to improve instruction in a variety of subjects and to serve disadvantaged students. Funds may be used to obtain telecommunications facilities and equipment, develop and acquire educational and instructional programming, and obtain technical assistance in the use of facilities and programming. To apply, applicants must form statewide or multistate telecommunications partnerships. Awards may be made for up to 5 years, with grantees required to provide matching funds.

Distance learning—FIPSE

Another program, the Fund for the Improvement of Postsecondary Education (FIPSE), supports projects that encourage innovative reform and improvement of postsecondary education. In recent years, FIPSE has supported a Comprehensive Program that awards grants for a wide-range of activities that foster improvement in higher education. This year, FIPSE is supporting a Special Competition instead of the Comprehensive Program. Funded for $9.5 million in fiscal year 1999, this Special Competition will award grants up to $1.5 million to institutions of higher education and other public and private nonprofit institutions and agencies. Awards will be made in 14 different subject areas identified by Congress, including enhanced distance education and teacher training activities. Application packages became available on March 16, 1999, and statements of intent to apply are due by April 16, 1999. Applications are due by April 30, 1999.

Enhanced distance learning—teacher training in technology programs

Two additional programs enhance distance learning by supporting teacher training in technology. The newly authorized Teacher Quality Enhancement Grants awards competitive grants to States to improve the quality of their teaching force through reform activities including teacher licensing and certification, accountability, and recruitment for high-need schools. The Department provides a competitive preference to those applications that propose to reform State teacher certification to ensure that current and future teachers possess the necessary teaching skills and academic content knowledge—this includes certification in information skills. The Teacher Training in Technology program, first funded in fiscal year 1999, will also help to improve teacher quality by awarding grants to consortia of States, institutions of higher education, and others to provide new teachers with intensive training and support in technology. Research shows that most institutions of higher education do not prepare teachers adequately to use educational technology. This

program helps to improve teacher quality by rectifying this shortcoming to ensure tomorrow's teachers can use technology effectively in the classroom.

State leveraging of education funds for enhanced distance learning systems

Several States have made a concerted effort to leverage the funds from various sources and to target specific needs with specific funds. Iowa, for example, has benefited from Technology Learning Challenge Fund (TLCF) and Star Schools grants to complete its fiber optic infrastructure throughout its 109 counties. Star Schools funds helped to build the infrastructure at the local level while TLCF funds were used primarily to support professional development activities.

In Kentucky, on the other hand, Star Schools funds were used to develop high quality student programming, as a result of partnerships with Kentucky Educational Television.

The Satellite Educational Resources Consortium (SERC) located in South Carolina, another Star Schools grantee, is an excellent example of several States pooling their funds together to develop excellent, high quality programming (some award-winning examples) that is then shared among its 23-State partnership of SEAs and public television stations. SERC States use their TLCF monies for professional development and some infrastructure redesign and use the Star Schools funds to support the demand for quality programming, content, and online resources.

Alaska currently benefits from Star Schools funding in two ways. They receive Star Schools programming through Spokane, Washington for such courses as Workplace Literacy, Young Astronauts, and core mathematics and science courses. This year the University of Alaska will receive $800,000 to deliver natural resources management courses as a result of directed funds.

PARENTING EDUCATION—BRAIN DEVELOPMENT IN EARLY CHILDHOOD

Question. As part of the informal Senate Brain Caucus, I have been fascinated by research that has been conducted during the "decade of the brain." This Subcommittee held hearings last fall on the critical importance of brain development during the period from birth through 3 years of age. That is the time when the brain sets the stage for all the future learning that occurs in life. Using a construction analogy, the brain builds either a small foundation or a big one depending on how much stimulation it receives—a small house or a huge skyscraper. The size of the learning foundation is established during those first 3 years. The key is to teach parents, especially new parents, how to stimulate their babies by reading and talking to them from the day they are born. Failure to do so or even worse, negative stimulation could result in learning problems that are difficult to overcome.

The Healthy Start Program in Alaska is seeking ways to incorporate parenting education into the classroom, including health classes. A GAO report indicates that children whose parents have participated in that program have higher high school graduation rates, higher grades, lower juvenile delinquency rates, and are more likely to go to college and enjoy greater success on every front later in life.

Have you looked at this issue, and if not, would you consider working with Secretary Shalala on ways we could help educate parents and future parents on basic parenting skills?

Answer. The Department is a part of the Early Childhood Research Working Group. This group is comprised of over 100 representatives from over 30 Federal agencies, across eight Federal departments, including the Department of Health and Human Services.

The purposes of the Working Group are to: (1) share current research findings, priorities, and other information across Agencies; (2) provide staff with professional development opportunities; and (3) develop channels for collaborative funding activities.

As a result of the working group meetings, several interagency activities have developed. For example, several agencies are planning a multi-year study of young children from very poor families. The children's developmental pathways from birth through early elementary school will be followed to determine factors that hinder and enhance the potential for school success by poor children.

QUESTIONS SUBMITTED BY SENATOR HERB KOHL

CLASS SIZE REDUCTION INITIATIVE—ALLOCATION PROBLEM

Question. As you know, I support legislation to hire 100,000 more teachers. However, I am concerned about one provision in both last year's and this year's legislation. It says that if a school district does not receive enough money to hire a full-

time teacher, that district must form a consortium with other districts and pool their money together to hire a teacher.

This simply won't work in rural Wisconsin—some districts are so small they qualify for less than $1,000; yet they are so geographically large that almost every child has to be bussed to the school. Many others only qualify for a few thousand dollars—a far cry from the average starting salary of a Wisconsin teacher. If these districts have to band together to hire one teacher, the only "three Rs" that teacher would deal with would be roads, railway tracks, and red tape.

Does the Administration support fixing this problem and fixing it on a retroactive basis, so that money appropriated last year can be used by all school districts?

Answer. Yes, the Administration does support providing school districts that receive a Class Size allocation that is less than the starting salary of a new teacher in that district with additional options beyond forming a consortium. We also would support allowing those additional options to apply to any funds received in fiscal year 1999.

Question. Would you support fixing it as a part of the Supplemental Appropriations bill, so that schools can use this year's money when it becomes available in July?

Answer. The Administration would support the change mentioned above if it were included as a part of a Supplemental Appropriations bill.

TEACHER MENTORING PROGRAMS

Question. I'd like to talk more about efforts to hire and retrain the best qualified teachers. Milwaukee Public Schools (MPS), in conjunction with the Milwaukee Teachers Education Association, have put together two successful teacher mentoring programs. The retention rate for teachers who participate is over 50 percent better than those who do not. However, while MPS hired 1,000 teachers last year, they only had enough money to provide mentors to 180 teachers. It seems to me that we could help schools expand their mentoring programs by providing additional funds.

What is the Administration's position on the usefulness of mentoring programs?

Answer. The Administration strongly supports induction programs for new teachers that focus on mentoring and other activities to help them strengthen their content knowledge and teaching skills. As you noted, these programs can also help to improve teacher retention rates, which is especially critical now that many school districts are experiencing teacher shortages.

ESEA REAUTHORIZATION—PROFESSIONAL DEVELOPMENT AND TEACHER MENTORING

Our proposal for the reauthorization of ESEA will likely include a program that consolidates Titles II and VI of the ESEA and the Goals 2000 program in order to link explicitly State content and student performance standards with professional development. As under the current Title II authority, a portion of the money would flow to institutions of higher education (IHEs) and the remainder to local educational agencies (LEAs). For both the LEA and IHE parts, our bill will likely authorize authorities to help schools assist new teachers during their first 3 years in the classroom. Such efforts could include year-long mentoring and coaching by trained mentor teachers; team teaching with experienced teachers; time for observation of, and consultation with, experienced teachers; assignment of fewer course preparations; and provision of additional time for course preparation.

Question. Would the Administration support an expansion of Federal funding for mentoring programs?

Answer. We do not envision proposing funding specifically for mentoring programs. Our reauthorization proposal would give school districts flexibility in using Federal funds to address their professional development needs. Mentoring programs would be a major use of the funds, but not the only allowable one. A flexible authority, such as this, would give districts the ability to increase support for mentoring if such an increase meets their needs.

TEACHER DIVERSITY

Question. I am also interested in programs that bring more people from diverse backgrounds into teaching. Coming from a business background, I believe that people from the private sector, particularly with expertise in math, science, or business, could also make good teachers. Unfortunately, it is difficult for mid-career professionals to leave their jobs for the 2-year period it would take to become teachers. Several proposals have been introduced to encourage States and school districts to create alternative teacher certification programs.

Does the Administration support alternative certification?

Answer. Our planned ESEA reauthorization proposal to consolidate Titles II and VI of the ESEA and the Goals 2000 program would allow States to use funds for developing alternative systems for teacher certification or licensure. We would strongly encourage them to develop systems that include the characteristics of high-quality alternative routes to certification that are described above.

"Troops to teachers" initiative

In addition to the funds that would be available through our reauthorization proposal, we are requesting $18 million for "Troops to Teachers" in our fiscal year 2000 budget request for the Fund for the Improvement of Education. This initiative will contribute to the Department's effort to help meet the need in the next decade for 2 million new teachers who are appropriately prepared to assist the growing student population to meet high academic standards. This program began in 1993 as a Department of Defense response to military downsizing. It has enabled military personnel to capitalize on their experience, while providing a new source of teachers with characteristics that address current areas of need. The Department proposes to build on the successful model that the Department of Defense has developed to recruit and prepare qualified retired military personnel as teachers and to expand this type of "alternative routes" effort to civilians who are interested in transitioning to a teaching career.

ALTERNATIVE ROUTES TO CERTIFICATION—RIGOROUS STANDARDS

Question. Specifically, what components must be included to make sure these programs are high quality?

Answer. Because there are many talented Americans whose rich experiences would allow them to contribute significantly to the education of children, alternative routes to certification can be a good way to attract talented mid-career professionals to the profession, especially in shortage fields such as math and science. That is why the Administration supports the development of rigorous alternative routes into teaching. However, rich experiences and content knowledge themselves are not sufficient for an individual to be an effective teacher. Teachers need to know not only their content, but also how to teach that content. For this reason, alternative routes should help individuals to develop strong teaching skills and, ultimately, should measure whether the individual has the knowledge and skills to be effective.

An alternative route that is high quality holds its candidates to the same standards as those for traditional candidates; it just provides a different route to meeting the standards. An alternative route should ensure that candidates have strong knowledge of the subject they will teach and knowledge of how children learn. It should also provide some means to assess candidates' effectiveness in a classroom setting through their prior experiences. When individuals are placed in a classroom, their teaching experiences should be heavily mentored during their first year as they learn to teach. They should be provided many opportunities to engage in training, to receive feedback, to have their teaching evaluated, and to work in diverse settings.

SPECIAL EDUCATION GRANTS TO STATES REQUEST

Question. One of the largest drains on school district budgets is the cost of special education. The Federal Government is supposed to pay 40 percent of these costs, but the President's budget only covers about 10 percent.

Why has the Administration provided this lower amount?

Answer. We believe that the legislative history surrounding the enactment of Public Law 94–142 in 1975, which served as the basis for the current Individuals with Disabilities Education Act (IDEA), indicates that members of Congress regarded the 40 percent as a goal, not a promise or commitment, and members acknowledged that the authorized amounts were not likely to be appropriated.

No additional funds are requested for the Special Education Grants to States program. However, our request includes $4.3 billion for funding this program. Since fiscal year 1996, funding for Grants to States has increased by almost $2 billion, or 85 percent. We believe that the current level of funding provides an appropriate level of support given the fact that States have the primary responsibility for educating all children, including children with disabilities.

There is a tendency to view the IDEA Grants to States program as the Federal program for providing assistance to States in serving children with disabilities. In fact, there are many Federal programs that assist States in serving these children, but they are not focused solely on children with disabilities. These programs include programs such as the Class Size Reduction program that helps schools hire highly qualified teachers and reduce class size; Eisenhower Professional Development State

Grants that help ensure that teachers, including teachers of children with disabilities, have the content knowledge to help children achieve to high standards; and 21st Century Community Learning Centers that provide a safe environment and expand learning opportunities for children before and after school. Federal subsidies for school construction bonds that will be used to repair, renovate, and construct schools will help ensure that our school buildings enhance the teaching and learning of all children, including children with disabilities.

With regard to programs that focus exclusively on children with disabilities, our request includes an the increase of $116 million. Most of the requested increases are for programs that will focus much-needed attention on addressing the needs of young children with disabilities birth through age 9. Our research indicates that the earlier we meet the needs of children with disabilities, the better the results. These programs include Grants for Infants and Families (+$20 million) to help States provide early intervention services for children with disabilities from birth through age 2 and their families, Preschool Grants (+$28 million) to help States provide special education services for children aged 3 through 5 with disabilities, and new Primary Education Intervention grants (+$50 million) that will help provide local educational agencies with the knowledge they need to improve results for young children with disabilities in the areas of reading and behavior.

We believe that our request reflects the best combination of programs and funding to address the needs of all children.

FUNDS FOR SPECIAL EDUCATION

Question. If more money were available for education spending, would the Administration work for a larger increase for Special Education?

Answer. We must always work within limited resources. The Administration must weigh many competing interests in determining Federal funding levels for various activities. The Administration would seriously consider increasing funding for Special Education if more money were available for education spending.

QUESTIONS SUBMITTED BY SENATOR DIANNE FEINSTEIN

TARGETING TITLE I FUNDS

Question. As I mentioned in my opening statement, I am concerned that in the Title I program, funds are not following the child and to me that should be the fundamental principle of the funding formula. I am particularly pleased that the authorizing law includes a provision that I worked on to require the Department of Education to allocate funds based on new child poverty data every 2 years. You have received this data and are trying to use it.

Don't you agree that funds should follow the child?

Answer. The Administration believes that, to provide the most effective services for children with the greatest educational needs, Title I must focus on the school as the unit of intervention, especially on schools with high concentrations of low-income children. These schools have the greatest need for Title I funds because they face the greatest challenges in educating their students to high standards. One challenge is that a high poverty rate has a negative impact on the achievement of all students in a school. In schools with a majority of poor students, all students are at risk of school failure.

Consistent with this general framework for targeting Title I funds and services to children in the highest-poverty schools, Title I funds should be allocated to where the poor children are, not to where they were a decade ago. The whole purpose of updating the poverty data in the Title I formula is to reflect, in the allocations, demographic shifts in the number of poor children.

TITLE I ALLOCATIONS—USE OF BIENNIAL UPDATED POVERTY DATA

Question. Don't you agree that the updated census data helps to implement that principle and helps guarantee that funding reflects the actual number of children?

Answer. Yes. Fair targeting depends on using the most current reliable data on the distribution of poor children. The Congress emphasized the importance of that principle in the 1994 reauthorization of Title I by basing allocations on poverty data that, beginning in 1997, are updated every 2 years rather than once a decade. However, because the appropriations acts in 1998 and 1999 included a 100 percent hold-harmless provision for both Basic and Concentration Grants, most districts received about the same amount of Title I funds as in the prior year despite the use of the new poverty data.

TITLE I HOLD-HARMLESS LANGUAGE

Question. Don't you agree that the "hold harmless" language violates that principle?

Answer. Yes. The special language in the fiscal years 1998 and 1999 appropriations acts included a 100 percent "hold-harmless" to ensure that each State and school district receive not less than its prior-year Title I allocation. This hold-harmless, which applied to both Basic and Concentration Grants, largely prevented the change to the new poverty data.

We strongly believe that special hold-harmless language should not be included in the appropriations bill, since the authorizing statute for Title I already provides a hold-harmless for Title I Basic Grants in an amount equal to between 85 and 95 percent of each district's prior-year Title I allocation, depending on the district poverty level. Inserting a 100 percent hold-harmless requirement prevents funds from flowing to districts that are gaining poor children, as documented by the updated data. The whole purpose of using updated data is to reflect, in the allocations, these population shifts. A basic principle in targeting should be to drive funds to where the poor children are, not to where they were a decade ago.

TITLE I ALLOCATIONS—USE OF UPDATED POVERTY DATA

Question. Do you support continuing to use the updated poverty data every 2 years?

Answer. Yes. In order to target the funds fairly, it is important to use the most accurate and up-to-date data available.

By requiring the use of updated data, Congress took something of a gamble in the 1994 legislation, because we (both the Congress and the Executive Branch) were uncertain that the Census Bureau could produce updated data that would be accurate enough for use in making Title I allocations. By 1998, however, the Bureau had developed a model for making updates that the National Academy of Sciences endorsed as superior to the older, decennial census data historically used for Title I allocations. With this model now available (and undergoing on-going improvements by Bureau), we should continue to use updated data in the program.

APPLYING TITLE I "HOLD HARMLESS" TO OTHER PROGRAMS

Question. The Title I formula is used in parts of other Federal programs, such as Goals 2000, Eisenhower Professional Development, Safe and Drug-Free Schools, and Educational Technology. According to the Congressional Research Service, it has become apparent that you are applying the Title I "hold harmless" language in the fiscal year 1999 appropriations bill to other programs, just repeating, in my view, the inequities and the violation of the principle that funds should follow the child.

Are you applying the Title I "hold harmless" to other programs in making allocations to States? If so, why?

Answer. For fiscal year 1999, like any other year, the Department is allocating Title I funds according to the statutory provisions governing the Title I formula, including the applicable hold-harmless provisions. State allocations under Title I have historically included a hold-harmless requirement with respect to Basic Grants. The difference for fiscal years 1998 and 1999, in particular, is that the appropriations acts have modified the hold-harmless provision to ensure that each school district and State receive an amount of Title I funds that equals not less than 100 percent of its prior-year allocation (under both Basic and Concentration Grants).

Legislation for the other State-administered formula programs, including Goals 2000 State Grants, Even Start, Eisenhower Professional Development, Safe and Drug-Free Schools, Education for Homeless Children and Youth, and Title III technology grants, requires that a State's allocation under those programs be based, in whole or in part, on the share of funds the State receives (or received in the prior year) under Title I. Consistent with these requirements, the Department is allocating fiscal year 1999 funds for these programs to each State according to the State's share of Title I funds. As in every other year, that share includes any hold-harmless amounts that are included in the Title I formula.

CALIFORNIA CLASS SIZE WAIVER

Question. Yesterday, I wrote you in support of the request of California's school Superintendent and Governor to recognize my State's extraordinary efforts to reduce class sizes in the early grades and to make sure California gets all the funds due us under this important program. As you know, in California, grades K–3 are at 18.94 students per class, and grades 1–3 are just barely above 19. In her February 19 letter, Superintendent Eastin asked you to substitute the number 20 for the cur-

rent number 18 as the trigger to allow California to use funds for further class size reductions in grades one to three, to reduce class size in kindergarten or other grades; or to carry out teacher quality initiatives. We have made extraordinary efforts, in a State that has 5.6 million students. California has more elementary and secondary education students than 36 States have in total population, so I hope you can agree that these are huge efforts. The February 29, 1999 San Jose Mercury News contains the following quote: "It makes a lot of sense to me," Riley said after meeting [with Governor Davis], noting California has nearly reached the class-size reduction levels set for kindergarten through third grade.

Can you assure me that you will give California full consideration of this waiver and recognize the advances we have made?

Answer. I can assure you that my staff will give California's request for a waiver from certain program provisions careful consideration and that we are well aware of the progress the State has already made in reducing class size in the early elementary grades.

Question. When will we have a decision?

Answer. We expect to have a final decision in early April.

GUNS IN SCHOOLS

Question. In 1994, I authored a provision requiring a 1-year suspension for bringing a gun to school. Your first report on this law categorized or quantified incidents, which is helpful, but it would be helpful to know if you think this law has cut down on guns in schools.

Do you think the Gun-Free Schools Act (GFSA) has cut down on guns in schools?

Answer. While no data are available that can precisely measure and isolate the effect of implementation of the Gun-Free Schools Act on the incidence of students bringing firearms to schools, preliminary data submitted by State educational agencies seem to indicate that fewer students are bringing firearms to schools, and anecdotal assessments of school security chiefs from several of the Nation's largest school districts appear to confirm this result.

Preliminary data submitted by the States under the GFSA suggest that the number of students reported to have been expelled for bringing a firearm to school in the 1997–98 school year will be significantly lower than the 6,093 such expulsions reported for the 1996–97 school year. However, the Department has not yet received 1997–98 data from every State, or completed procedures to verify the data.

Department of Education officials met recently in California with a group of school security chiefs representing some of the largest school districts in the country. The meeting included representatives from the school systems in Oakland, San Francisco, Long Beach, Los Angeles, San Bernardino, Pasadena, and Compton, as well as from other large school districts around the country. The chiefs consistently indicated that fewer students in their districts are bringing firearms to school.

We believe that the GFSA has played an important role in reducing the number of students who bring guns to school. The GFSA has significantly increased awareness of this important issue among education officials at the State and local levels, and implementation of the GFSA has resulted in concrete actions by virtually every local educational agency (LEA) in the country to keep guns out of schools: under the GFSA, LEAs have adopted policies required by their State laws, and implemented the sanctions required by those policies. These actions have let students and parents know that school officials believe that children and firearms in a school setting are a dangerous mix that cannot be tolerated if schools are to remain safe and disciplined environments, conducive to learning.

OTHER WEAPONS IN SCHOOLS

Question. The California Department of Education released their safe schools assessment on February 24 and reported that the number of guns seized fell for the second straight year, but there was a 16 percent rise in the number of knives. There have also been reports of anthrax releases in the schools.

Should we broaden the law to include other dangerous weapons, as we did in the Individuals with Disabilities Education Act (IDEA) law?

Answer. We believe that the scope of the GFSA should continue to be limited to firearms and explosive devices, as under current law. While we are very aware of the danger of other weapons in the school environment, we have several concerns about broadening the requirements of the GFSA to include other weapons, such as knives.

We are concerned about how a modification to the GFSA could be written to define and describe appropriately the other weapons that should be included in an expansion of the existing requirement. Recent news stories that have received exten-

sive coverage seem to indicate that local attempts to define items to be included in a "weapons" policy have resulted in unintended consequences, including the expulsion of students for bringing fruit knives or other implements used as eating utensils. We also know from talking to security officials at local school districts that items commonly found in schools and never intended to serve as weapons (e.g. baseball bats, earrings) can be used to harm teachers and students.

This difficulty, coupled with our very significant concern about the volume of expulsions that could result from such an expansion to the law, has led us to conclude that this issue is best left to the discretion of local school boards and educational officials. We believe that expelling students without providing them with educational services disconnects these troubled youth from caring adults, takes away their hope for the future, and leads them to a lifestyle of increased crime and delinquency.

The GFSA does not limit the authority of States or LEAs to adopt policies requiring the expulsion of students for other weapons violations, a fact that the Department clearly explains in its non-regulatory guidance on implementation of the GFSA.

Question. Should we try to address biological weapons in the schools?

Answer. We plan to carry out some activities on this topic in conjunction with the U.S. Department of Justice, including development of materials and provision of technical assistance; however, we do not believe it is necessary to broaden the scope of the GFSA to address biological weapons in schools. We are not aware of any instances where anthrax or other biological weapons have been brought to, or released in, a school setting. Fortunately, it appears that it would not be easy for students to acquire anthrax or other biological material that could be used as a weapon. Officials from the Federal Bureau of Investigation (FBI) participated in the recent school security chiefs meeting to discuss how to deal with possible terrorist activity (including threats related to biological weapons) in schools. FBI officials encourage local school officials to become more closely linked with existing disaster preparedness and planning activities in their communities so that they will be familiar with appropriate procedures in the event of an incident.

REQUEST FOR ZERO FUNDING FOR THE TITLE VI PROGRAM

Question. The President's Budget requests no funding for the Title VI block grant program, yet California schools rely on the flexibility of Title VI funds. For example, Fresno Unified School District used funds for a summer school program designed to help students experiencing academic difficulty. Parents and the community became involved, teachers received training and administrative support, and students made measurable gains in both reading and mathematics. Also, Title VI funds helped strengthen and expand Manteca Unified School District's staff development program for new teachers called "Good First Training," which is focused on a balanced approach to literacy. Training sessions included live demonstrations and opportunities for immediate practice.

Given the flexibility of Title VI, why did you request zero funding for the program?

Answer. The Administration believes that the Title VI program is not well designed to support the types of State and local efforts that can result in real improvements in teaching and learning. Findings from the most recent evaluation of the former Chapter 2 program, Title VI's predecessor, suggest that programs that offer the flexibility of Title VI, but provide greater accountability, have a better chance of effecting real change in the classroom. For example, the evaluation found that program funds were used by fewer than half of the States to support such reform efforts as revising and developing standards for student performance, developing alternative measures of student achievement, or encouraging public-private partnerships. Districts were even less likely than States to use Chapter 2 funds to support education reform efforts. Although more than half of all districts reported some systemic reform efforts, fewer than one-fourth of them used Chapter 2 funds to support these activities.

The evaluation also found that local educational agencies (LEAs) tended to use their Chapter 2 expenditures for purchases of instructional materials rather than for educational reform activities. In addition, States and LEAs sometimes used Chapter 2 funds for activities and programs that were not directly related to classroom instruction; for example, LEAs often purchased equipment for administrative use, and SEAs used Chapter 2 funds for various administrative activities. The evaluation also found that the majority of activities supported by Chapter 2 funds would have continued without Chapter 2, because these funds typically constituted a small percentage of any program's funding.

The Department believes that a more effective way to utilize scarce resources lies in targeting funds on comprehensive systemic reform and areas of high need. For example, programs under the Goals 2000: Educate America Act provide almost the same flexibility as Title VI, but make the critical link between expenditures and educational reform that Title VI does not. States are using Goals 2000 funds to establish challenging academic standards and to coordinate their curriculum frameworks, student assessment programs, and other aspects of their educational systems to help children achieve to the State standards.

ESEA Reauthorization—consolidation proposal

The Administration's reauthorization proposal for ESEA will likely consolidate Titles II and VI of the ESEA and the Goals 2000 program to explicitly link State content and student performance standards to professional development activities. This program would allow States and school districts to continue to develop content and student performance standards and to develop, implement, and improve assessments and curricula that are aligned with those standards. The program also would focus strongly on professional development that is content-based, sustained, collaborative, and tied to State and local standards.

Program funds at both the State and local levels would be used for these activities. We believe that such a program would give States, school districts, and institutions of higher education the flexibility they need to improve instruction in our Nation's classrooms and to continue implementation of challenging performance standards that are designed to raise student achievement.

SOCIAL PROMOTION

Question. President Clinton will send to Congress a significant reauthorization of the ESEA. Accountability is a major part of the President's education proposal. Part of the message of accountability is ending the practice of social promotion. I support ending the practice of social promotion. I also recognize the importance of implementing policies that improve teacher training and prepare students to graduate.

Specifically, how do you propose we ensure that schools and teachers are accountable for student achievement?

Answer. The President's call for an end to social promotion is designed to tell students that "performance counts," and to encourage districts and schools to take aggressive action to help all students meet promotion standards on time. We are not encouraging school districts to end social promotion by retaining students in grade; instead, we will be asking school districts to educate children to high standards. That is why we have pushed so hard for programs like Class Size Reduction, the Reading Excellence Act, and the 21st Century Community Learning Centers afterschool initiative, which help to minimize the number of children at risk of retention in grade.

Our approach to accountability will include a range of options for helping to ensure that schools and teachers help all students meet high standards required for promotion to the next grade. For example, our reauthorization proposal would give school districts greater flexibility if they are moving in a positive direction for all students. But if a school district is not progressing, State and local officials will need to find out why and then take appropriate steps to improve academic achievement. They should look at teacher training, student achievement, discipline in the school, the public reporting of how well the schools and school districts are doing, and the offer of special help to students who need the assistance. We will help, prod, nudge, and demand action, if necessary.

Effective strategies to end social promotion include early identification and intervention for students who need additional help(including appropriate accommodations and supports for students with disabilities and students with limited English proficiency. After-school and summer-school programs, for example, can provide extended learning time for students who need extra help to keep them from having to repeat an entire grade. We believe that States should target their efforts at key transition points, such as 4th, 8th, and 10th grades, and should use multiple measures, such as valid assessments and teacher evaluations, to determine if students have met high standards required for promotion to the next grade.

ESEA Reauthorization—provisions to end social promotion

Our reauthorization proposal will take into account these and other elements that are necessary for a successful policy to end social promotion. We are considering requiring that each State and school district receiving ESEA funding adopt a policy and plan to end social promotion, and that the policy ensure that children at risk of retention in grade be provided early intervention support to achieve better results. Likewise, we anticipate requiring districts to have carefully developed dis-

cipline policies in place. While we expect to provide substantial flexibility in how a State or local district addresses these matters, we also want to create meaningful provisions to address the problem. The Department's role will be to ensure that each State and school district that receives ESEA funds has addressed the issue in a meaningful way.

FEDERAL EDUCATION FUNDING

Question. Over the last 3 years, Federal education funds have increased by approximately $10.4 billion. However, Federal funding of elementary and secondary education is still only 6 percent.

Do you think the Federal Government's spending on education is adequate?

Answer. The Federal investment in education must be considered in the context of the overall Federal budget, including such concerns as meeting the discretionary caps and ensuring the soundness of our Social Security and Medicare systems. With that caveat, I favor increased Federal resources for education in areas of national priority where we can ensure accountability for results.

Question. How much would you increase the funding levels if you had your choice without budget constraints?

Answer. I don't have a specific total in mind, but I would consider significant increases to expedite the hiring of 100,000 teachers to reduce class sizes in the early grades, to improve services under the Individuals with Disabilities Education Act, to raise the maximum Pell Grant award for low-income postsecondary students, and to improve teacher quality.

FIFTH YEAR PELL GRANTS

Question. Last year, with your support, Congress adopted my amendment to allow you, the Secretary, to award on a case-by-case basis Pell Grants for disadvantaged students for the fifth year of teacher education required in California to get a teaching credential. This could enable 12,000 disadvantaged students to become teachers in my State at a time of great need.

What is the status of implementing this change, and is it now available to students? If not, when will it be?

Answer. All regulations related to Title IV of the Higher Education Act (HEA) are now subject to the requirements of both negotiated rulemaking and the master calendar (sections 492 and 482, respectively). Consequently, this new provision which expands Pell Grant eligibility for students enrolled in non-graduate postbaccalaureate teacher certification programs is currently under discussion as part of ongoing negotiations with the higher education community. Final regulations are expected by November 1, 1999, to be effective for the 2000–2001 award year.

However, we have also taken steps to implement this provision for institutions and their students starting with the current (1998–1999) award year. We have provided both the University of California and the California State University systems with information on what their institutions must do in order for their students to take advantage of this new provision in the current year. More specifically, we have provided both university systems with "workarounds" for the Title IV application processing system to enable their students, who would otherwise be ineligible for Pell Grants because they have already obtained baccalaureate degrees, to receive Pell Grants (assuming all other eligibility criteria have been satisfied) this year.

The Title IV application processing system will be modified for the 1999–2000 award year so that the current "workaround" will be unnecessary.

STUDENT LOAN DEFAULTS—STUDY OF FEW BORROWERS

Question. Congress also accepted my amendment to require the Department to do a study of student loan default calculations because the community colleges in my State said that the current method makes it appear that they have a very high default rate when they have just a few borrowers. Your study is due on September 30, 1999.

What is the status of that report; will we get it on time?

Answer. The Department is currently conducting the analysis as requested and expects to submit the report on or before September 30, 1999.

BILINGUAL EDUCATION

Question. Many believe that bilingual education, instead of being the transition to English as it was intended, has delayed students from learning English.

Do you think Bilingual Education works?

Answer. The Department believes that the vast majority of projects we assist under the Bilingual Education Act do a good job of teaching English to limited English proficient students and assisting them to achieve to high academic standards. Projects funded under the Federal Bilingual Education Act are by law given considerable latitude in designing a program that best meets the needs of the particular students served by the grant. Some of our projects incorporate the use of the native language in the instruction of academic subjects while students learn English, an approach generally known as bilingual education. Other projects use only English for instruction. The majority of our grantees combine approaches in ways that best meet local needs. One of the great strengths of the current statute is that it permits us to fund a wide range of instructional approaches.

ESEA REAUTHORIZATION—BILINGUAL EDUCATION PROPOSALS

Question. Do you plan major changes in your ESEA reauthorization proposal?

Answer. Our current thinking is to propose a number of changes to the current statute to incorporate the Department's goal that limited English proficient students become proficient in English within 3 years. We also expect to make proposals to increase project accountability and to make the program more effective in meeting the educational needs of the Nation's fast-growing limited English proficient student population.

ACHIEVEMENT STANDARDS FOR ENGLISH FOR LIMITED ENGLISH PROFICIENT STUDENTS

Question. Do you think States should develop achievement standards for students learning English?

Answer. In principle, limited-English proficient students should be held to the same high standards expected of any other students. These standards should address both the acquisition of English and the mastery of academic content area, such as math or reading. In practice, it is important for States to proceed carefully when developing achievement standards for English for limited English proficient (LEP) students because of the many unique variables associated with this population, including but not limited to, the length of time a LEP student has been in schools and the student's literacy skills in the native language. Model standards for teaching English as a second language are published by the Teachers of English to Speakers of Other Languages group.

IMMIGRANT EDUCATION PROGRAM—FLAT BUDGET

Question. Immigrant students have many needs. Many have had little or severely interrupted schooling in their home countries; they often live in poverty; reside in multiple family dwellings; speak little English; and are facing major adjustments. Your budget requests only $150 million, the same as we appropriated last year. This works out to $180 per immigrant student in California. This does not begin to address their needs, and immigration is, after all, a Federal responsibility.

Why haven't you requested more?

Answer. In response to the Administration's proposals, Congress doubled funding for this program in fiscal year 1997 from $50 million to $100 million and increased it by another $50 million in fiscal year 1998. Last year the number of eligible students served by this program declined by 65,000. We agree with your assessment of the needs of these students, but do not believe that further increases in Immigrant Education funding are warranted at this time.

OTHER PROGRAM FUNDS FOR EDUCATING IMMIGRANT CHILDREN

Question. Don't we need to put more resources into helping these children learn and become productive?

Answer. We need to make sure there are sufficient resources to ensure that immigrant students learn and become productive. However, we do not believe that the Immigrant Education program is the best vehicle for ensuring this result. In fiscal year 2000 we propose a $320 million increase in Title I funds and a $35 million increase in funding for the Bilingual Education program. These programs serve large numbers of immigrant students and are a better investment in improving educational services for these students than further increases in Immigrant Education.

SCHOOL CONSTRUCTION NEEDS IN CALIFORNIA

Question. I applaud your school construction initiatives, coming from a State that has enrollment projections at three times the national rate. After passing a school bond last fall, we will need $26 billion over the next decade. California's construc-

tion costs are higher than many States. Seismic requirements add 4 percent to the cost of a school.

Will you take these factors into consideration in awarding school construction grants?

Answer. Under the Administration's proposal, federally subsidized bonds, rather than grants, would be used to support the construction, rehabilitation, or repair of public schools. States and some school districts would be allocated these bonds. While grants would not be provided, the Administration's proposal includes a provision that would enable the Secretary of Education to take school construction needs into account when distributing a portion of the bond authority.

The bonds would be subsidized by Federal tax credits, provided to bond holders, that would be approximately equal to the interest payment on a taxable bond. All States and the 100 school districts with the largest number of children in poverty would receive direct allocations of this bonding authority. The bonding authority would be distributed to States and school districts using a formula based on their share of Title I funds. In addition, the proposal includes a provision for the Secretary of Education to allocate a portion of the subsidized bonds for up to 25 additional school districts that are in particular need of assistance. Need would be determined by a low level of resources, a high level of enrollment growth, and other factors the Secretary determines appropriate. The Secretary could consider construction costs in certain regions when selecting these 25 school districts.

SUBCOMMITTEE RECESS

Senator SPECTER. The subcommittee will stand in recess to reconvene at 11 a.m., Tuesday, March 23 in room SD–192. At that time we will hear testimony from Hon. Alexis Herman, Secretary of Labor.

[Whereupon, at 10:40 a.m., Wednesday, March 3, the subcommittee was recessed, to reconvene at 11 a.m., Tuesday, March 23.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2000

THURSDAY, MARCH 23, 1999

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 11 a.m., in room SD–562, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter and Gorton.

DEPARTMENT OF LABOR

OFFICE OF THE SECRETARY

STATEMENT OF HON. ALEXIS M. HERMAN, SECRETARY

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The hour of 11 o'clock having arrived, we shall proceed with the Appropriations Subcommittee on Labor, Health and Human Services, Education.

We will await momentarily the arrival of the Secretary. [Pause.]

Now that we have waited for a moment, we will issue a subpoena. [Laughter.]

In the criminal courts in Philadelphia, at this point the judge would send some bailiff into the courtroom's corridor to see if the parties or witnesses were in the corridor. [Pause.]

Good morning, Madam Secretary.

Secretary HERMAN. Good morning, Mr. Chairman.

Senator SPECTER. We have just forfeited $500 million a minute——

Secretary HERMAN. Oh, my goodness. [Pause.]

Senator SPECTER [continuing]. Which, in light of your magnificent red dress, will be reinstated promptly.

Secretary HERMAN. Thank you very much.

Senator SPECTER. This morning, the Subcommittee on Labor, Health and Human Services, Education will continue its hearings on the President's fiscal year 2000 appropriations request.

We are pleased, once again, to welcome the distinguished Secretary, Hon. Alexis Herman. The department's budget request for discretionary spending for fiscal year 2000 totals $11.6 million, an increase of $600 million, or 6 percent, over last year.

As you can see from the chart on the right (indicating), there are difficulties faced with the proposed savings of some $18 billion in increased fees, taxes, and mandatory savings proposed by the President.

The second chart identifies the $18 billion in offsets, most significantly the $8 billion in Federal tobacco revenues, which are evanescent, illusory, and really gone, and a reduction of $6.8 billion in mandatory spending.

We have grave difficulties, but we will do our best to tackle them. We appreciate the cooperation of the distinguished Secretary of Labor in our open lines of communication and her efforts to be of assistance, with the reciprocal efforts of this subcommittee and the full Congress to be of assistance to the Secretary in her important work.

SUMMARY STATEMENT OF HON. ALEXIS M. HERMAN

Welcome. Your full statement will be made a part of the record. We will not use the lights. The floor is yours.

Secretary HERMAN. Thank you very, very much, Mr. Chairman. As always, we thank you for your support of our work.

Permit me to make a brief opening statement and, of course, at that time I will be happy to answer any questions that you may have.

To you, Mr. Chairman, let me say that it is an honor for me to join you once again and to have this opportunity to discuss the fiscal year 2000 appropriations request for the Department of Labor—a budget that is designed to close the skills gap, open the doors of opportunity and meet the Nation's challenges in a new economy and a new century.

As we look to that agenda, I want to begin by thanking all of the members of this subcommittee who are helping us develop the right strategies to better the lives of working families. Our request for appropriations for fiscal year 2000 builds on our progress together.

Specifically, the department's fiscal year 2000 budget request totals $39.6 billion, of which $13.3 billion is subject to the annual appropriations process and is now pending, Mr. Chairman, before your subcommittee.

The request for discretionary programs is $11.6 billion in budget authority, which is $626 million above the fiscal year 1999 level.

Against the backdrop of our strong economy, I have set three strategic goals for the Department of Labor: a prepared workforce to ready all Americans for the opportunities in the new economy; a secure workforce to insure that no one is left behind; and quality workplaces, ones that are safe, healthy, and fair, meaning free of discrimination.

When I speak of the challenge of a prepared workforce, we know that, in spite of record low unemployment, millions of Americans are having difficulty finding new jobs or moving up the career ladder. Every day, employers tell me that they are having trouble finding qualified workers. But, as Secretary of Labor, I have often said that we don't have a worker shortage in this country but we do have a skills shortage. We need to close that skills gap and open new doors for working families.

That is why our budget includes for the fiscal year 2000, funding to help States and local communities implement the Workforce Investment Act. We are also seeking $368 million for what we call the Universal Re-employment Initiative. We propose to reauthorize the Welfare to Work Program in fiscal year 2000 and we want to put a special emphasis on noncustodial parents, most of whom are fathers.

We propose to continue our $250 million investment in Youth Opportunity Grants, to reduce unemployment in high poverty areas for our young people. We don't have a person to waste in this country let alone, Mr. Chairman, a full generation to lose. We especially appreciate your leadership and your commitment in this area.

As we prepare workers, we must also preserve and expand the economic security of working families. So my second strategic goal is insuring a secure workforce.

To meet this challenge, our budget includes $11.8 million to increase pension plan and health coverage. We want to reward work and raise the minimum wage by $1 an hour over the next 2 years, and we are committed to a strong and enforceable Patients' Bill of Rights.

My final strategic goal is fostering quality workplaces, ones that are safe, healthy, and fair. Our budget invests in innovative safety and health programs in the Occupational Safety and Health Administration and the Mine Safety and Health Administration to protect workers, inform employers, and enforce our laws. We are moving forward to develop a proposed ergonomics standard this year.

We have also targeted abusive and exploitative child labor both at home and abroad through a comprehensive strategy of enforcement, education, and partnership.

I want to congratulate Senator Harkin and to thank him for his leadership in this area. As you know, we are now the leader in the ILO's program for the elimination of child labor and we are grateful for the $30 million provided by Congress last year. We are proposing to continue that level in fiscal year 2000.

I am also committed to working with the ILO and all of you on a new initiative to improve labor standards around the world. We are requesting $35 million for this effort.

Here and at home, we must also step up our efforts to insure that women and men earn equal pay for equal work. That is why the President's Equal Pay Initiative includes $4 million to invest in our efforts to increase outreach, education, and technical assistance in this area.

Above all, we need strong enforcement of all of our laws, not only to ensure equal pay for equal work but, to end pay discrimination, and to see that women have equal opportunity in all levels of the workforce.

That is a very broad sketch of our agenda: a prepared workforce, a secure workforce, and quality work places. I know that even though we have three strategic goals at the Labor Department and many initiatives within each, there is only one way to succeed—not as separate agencies but as one Department.

PREPARED STATEMENT

This is why I take very seriously our strategic management process and GPRA for managing for results.

I look forward to working with you and with all of the members of this committee on these important initiatives to improve the lives of America's working families.

Now I will be happy to answer any questions that you have, Mr. Chairman. Thank you very much.

[The statement follows:]

PREPARED STATEMENT OF ALEXIS M. HERMAN

Mr. Chairman and Distinguished Members of the Subcommittee: I am pleased to be here with you today to discuss my fiscal year 2000 request for appropriations for the Department of Labor.

My request for appropriations for fiscal year 2000 builds on the successes of the past six years. Under the leadership of President Clinton, the American people are enjoying the first budget surplus in 30 years. This Administration has presided over the longest peacetime economic expansion in our history. Over 18 million new jobs have been added. Wages are rising at more than twice the rate of inflation. Welfare rolls are down, while home ownership is up. Unemployment is at its lowest peacetime rate in over 40 years.

HELPING WORKING FAMILIES MANAGE CHANGE

Though the economy is strong, the dynamic forces of technology, globalization, and competition are sending changes through the workplace. Large firms, which provided stable employment, and a stable climate for regulation and enforcement, are now complemented by a dynamic world of small and medium-sized business startups, often in new lines of industry. Many new jobs are in these smaller firms, and many new workers now work in them. We must help working families as they attempt to adapt to these changes.

ADDRESSING WORKERS' PROBLEMS STRATEGICALLY

Against this backdrop we are preparing for the challenges of the 21st century. I believe that government must be fiscally responsible as well as dedicated to giving people the tools they need to succeed. With this in mind, I have set three strategic goals for the Department of Labor: promoting a prepared workforce, a secure workforce, and quality workplaces. Those overriding goals are based on underlying value—opportunity and responsibility, community and family, justice and fair play. Let me explain.

A Prepared Workforce.—My budget request reflects one of the President's top priorities: investing in education and training to ensure that every American has the schooling and the skills to succeed in the increasingly competitive global economy. The Workforce Investment Act (WIA), incorporating the President's principles of job training reform, expands the One Stop system of streamlined service delivery to job seekers and employers, empowers customers with the resources and information to select training that meets their need through Individual Training Accounts and "Consumer Reports" on training provider performance, and authorizes Youth Opportunity Grants, to help boost employment among young people living in high poverty urban and rural areas. WIA was a bipartisan effort and enjoys continued bipartisan support. It requires that all States be fully operational by July 1, 2000. It is essential that adequate funding, as proposed in my fiscal year 2000 budget request, be provided to assure States' and local communities' success in implementing this key reform.

In the new economy, and on the edge of a new century, education cannot end with a high school diploma, or even with a college degree. Now, education must mean lifelong learning and continued development of new skills.

A Secure Workforce.—We receive thousands of letters from people who discover after they retire that they do not have the retirement benefits they expected. This is one reason I believe it is critical that we step up our efforts to ensure that all Americans are economically secure after they retire. Employment-based pension and health benefits are the foundation of family security.

I am troubled by the fact that only about one-half of all full-time workers in the private sector have pension coverage. Three-quarters of workers in small businesses

are not covered by a pension plan. Increasing access to our private pension system and assuring that private pensions, health care, and other employee benefits are secure and properly administered are among my most important priorities and are addressed by this budget. Several initiatives have been designed to achieve significant progress in helping to promote an economically secure workforce, such as safeguarding pensions and health care plans which I will describe in more detail later in my statement.

Finally, a secure workforce requires a fair minimum wage. Today, a full-time minimum wage worker earns approximately $10,700—$2,900 below the poverty level for a family of three. In the midst of the greatest peacetime expansion in the Nation's history, this is unacceptable. A hard day's work deserves a fair day's pay. We must raise the minimum wage by $1 an hour over the next two years. I hope that we can work in a bipartisan fashion to enact this legislation.

Quality Workplaces.—My third goal is to guarantee every working American a safe and healthful workplace with equal opportunity for all. If an employer's practices threaten workers' safety and health, discriminate on the basis of gender, race, color, national origin, religion, veterans' status, or disability, or deprive workers of fair wages, then tough enforcement becomes a necessity. Our ultimate goal, however, is compliance with employment laws. My emphasis is to ensure an appropriate balance of fair and consistent enforcement, compliance assistance, training and cooperative partnerships. I am also committed to improving working conditions at home and abroad by aggressively working toward the elimination of abusive child labor and by promoting international core labor standards, which I believe will enhance economic growth and stability abroad.

GAPS BETWEEN SKILLED AND UNSKILLED WORKERS STILL EXIST

As I mentioned earlier—unemployment is at its lowest level in a generation. Be they young or old, women or men—many more Americans who want a job can find one. That's good news for working families.

However, the continuation of a large gap in employment and earnings between less-skilled under-educated workers and the rest of the labor force is well-documented, and must be addressed if America aspires to be a Nation where hard work is rewarded fairly.

The Administration has instituted policies that have helped to begin narrowing this gap, but more remains to be done.

In addition to the wage gap, research shows that there are continuing gaps in other important aspects of workers' lives—in training, benefits, and working conditions.

Not that long ago, some policy and program analysts held that non-wage benefits and working conditions acted as a leveling influence on wage gaps. Now, we see that benefits and better working conditions tend to be associated with higher paying jobs—in other words the gap in real wages is actually wider when we include benefits in the calculation. While highly skilled, educated workers have enjoyed the benefits of economic growth, low skilled, low wage workers have not kept pace. And so I want to be clear that workers also experience disparities in other areas—safe and healthful working environments, fair and equal opportunities and in workers' rights.

My strategic goals of promoting a prepared workforce, a secure workforce and enabling workers to perform in high quality workplace environments are intended to help close these gaps.

I believe that the Department's budget request is both innovative and responsible—it takes account of the dramatic changes that continue to sweep through the economy, and proposes ways to help America's working families succeed in the new environment. It reflects my priorities to provide assurance that all workers have the opportunity to find and hold jobs, under high quality working conditions, with good wages, safe pensions, health benefits, and opportunities to improve their skills.

For these purposes, the Department's fiscal year 2000 budget proposals total $39.6 billion, of which $13.0 billion is subject to the annual appropriations process and is now pending, Mr. Chairman, before your Subcommittee. The request for discretionary programs is $11.6 billion in budget authority, which is $0.6 billion above the fiscal year 1999 level.

FISCAL YEAR 2000 BUDGET PROPOSALS—CLOSING THE GAPS

My budget request for fiscal year 2000 proposes several programs and innovations, all of which are focused upon narrowing or closing the gaps in wages, benefits and working conditions.

Closing the skills & wages gap

I am proposing several programs to address the wage gap and advance my goal to promote a prepared workforce.

Education and training

Despite the low overall unemployment level, there are still pockets of Americans who want to work but have difficulty finding new jobs. At the same time, employers across the country tell me they cannot find qualified workers. I don't believe we have a worker shortage. Instead, we have a skills shortage. I believe we must give Americans who want to work the skills to ensure they can get and keep a decent job.

In fiscal year 2000 I propose to make substantial progress toward creating a 21st century reemployment system. My proposal would ensure that we move toward: (1) helping all dislocated workers who want and need services with resources for training or to find new jobs; (2) expanding and enhancing the quality of employment services available for workers receiving UI and other job seekers who have lost their jobs; and (3) ensuring that any job seeker has access—in person or in the rapidly expanding world of electronic communication—to a core set of employment-related services through One-Stop Centers. My budget includes an increase of $368 million for a Universal Reemployment Initiative as a first step toward achieving this goal.

For assistance to Dislocated Workers, I am requesting a total of $1.6 billion, an increase of $190 million, to provide readjustment services (including job search assistance), skill training and related services to help an estimated 858,500 dislocated workers find new jobs as quickly as possible. This is the initial downpayment on a five-year investment to ensure that all dislocated workers, who need it, receive assistance.

Included within the $190 million increase is $40 million to provide dislocated worker training and job placement services in industries and occupations experiencing skill shortages. Although funding is requested now for this program, legislation will be proposed to finance it through fees paid by employers applying for foreign workers through labor certification programs.

Also in fiscal year 2000, I am requesting $53 million for Reemployment Services Grants to State Employment service agencies. These grants will provide funds for increased reemployment services to unemployment insurance claimants to ensure that all unemployed workers who need help to become reemployed will get the help they need. The increase will target staff assisted services to insured unemployment claimants, providing early intervention and immediate referrals to suitable job openings to help them get jobs faster reducing their period of unemployment and benefit costs. For those in need, State Employment Service staff will provide customized services including workshops, job search assistance and screening for referrals to training or other support services.

I am proposing to continue development of a One Stop Center System, as authorized by WIA, to transform a fragmented array of employment and training programs into an integrated service delivery system for adults seeking to advance their careers. The fiscal year 2000 request is $149 million, which includes a $65 million set of initiatives to develop new ways to provide employment-related information through America's Labor Market Information System—an essential part of the One-Stop service delivery system that is now required in the WIA. Some examples of new ways we intend to provide services are a "talking" America's Job Bank for the visually impaired, mobile service centers for rural areas, a 1–800 number providing the entire customer base of the workforce investment system with information on public workforce services available at a location most convenient to them, and continued enhancements in America's Job Bank, America's Talent Bank, and America's Career InfoNet.

The fiscal year 2000 budget also includes $10 million for the second year of the joint Labor Education Learning Anytime, Anywhere Initiative to enhance and promote learning opportunities outside the usual classroom settings via computers and other technology for all adult learners.

I am also proposing an additional $10 million for the new America's Agricultural Labor Network (AgNet). I view this as an important step in assuring U.S. farmworkers have increased access to jobs, better wages and working conditions. I see AgNet as a resource for growers to find domestic farmworkers instead of being reliant on international labor markets. AgNet would automatically be available through local libraries, unions, community-based organizations, State Employment Security Agencies and Department of Agriculture extension offices. Basic job information from AgNet also would be available in "America's Job Bank."

In fiscal year 2000, I am also requesting $50 million for new Work Incentive Grants. This is part of the President's comprehensive initiative to provide economic

opportunities for people with disabilities. This will provide competitive grants to partnerships of organizations in every State, including organizations of people with disabilities, to help One-Stop Career Centers and Workforce Investment Boards provide a range of high quality services to individuals with disabilities to allow them to return to work or obtain employment.

As another important piece for closing the wages and skills gap, I am proposing an fiscal year 2000 level of $2.8 billion for the Department's Youth Programs, a net increase of $68 million above fiscal year 1999.

Included in the request is $1 billion for Youth Activities, authorized by WIA. This program replaces Job Training Partnership Act Youth Training Grants and Summer Youth Employment and Training with a single funding stream that provides local flexibility to support a wide range of activities and services to prepare disadvantaged youth for academic and employment success, including summer jobs. An estimated 577,700 participants will be served at the requested level.

My request also includes $250 million to continue the Youth Opportunity Grants at the level at which it was funded in fiscal year 1999. These competitive grants address the special problems of out-of-school youths, especially in inner-cities and other areas where jobless rates can top 50 percent. The initiative takes a saturation approach to solving high unemployment, investing large amounts of resources in high poverty areas to increase educational and economic opportunity. Grantees will use case managers and job developers to place and maintain youth in private sector jobs. Education, job training, and work experience slots will be available for youth not ready for private sector placement. Related goals include reducing dropout rates, teen pregnancy, and crime; and increasing enrollment in post-secondary education.

The budget also includes $100 million for a new Right Track Partnership (RTP) initiative of competitive grants designed to prevent economically disadvantaged and limited English proficient youth from dropping out of school and to encourage those who have already dropped out to complete their high school education. Building innovative partnerships between the private sector, school districts, and community based organizations, RTP will provide comprehensive services and economic opportunity to youth in high poverty areas.

For the Job Corps, I am requesting an increase of $38 million to continue the operation of 118 existing centers plus an additional 3 new centers scheduled to be activated in 2000. Increases are requested for post-program termination and follow-up services, teacher/staff salary increases, and operating costs of new centers. In addition, funding is requested to complete the last of four new centers for which construction was initiated with 1998 resources.

The budget includes $110 million (equally divided between DOL and Education) to complete the final year of Federal funding for the School-to-Work Initiative. Since 1995, this initiative has made over $1.7 billion available to States and local communities to build comprehensive systems that link Federal, State, and local activities to help young people move from high school to careers or post secondary training and education.

Ensuring a prepared workforce also requires us to continue the work of welfare reform and that is the reason I have included a request for $1 billion to continue the Welfare-To-Work jobs initiative. With the current healthy economy, characterized by low unemployment rates and labor shortages in some areas, the Nation has unprecedented opportunity to move a substantial portion of hard-to-serve welfare recipients into unsubsidized employment with career potential. This is good news. But the hardest work lies ahead, because those still on the rolls face the biggest challenges to employment. So, we propose a one-year, $1 billion reauthorization of Welfare-to-Work that would retain the program's strong focus on long-term, hard-to-employ recipients. These funds not only help people get jobs—they will help people keep their jobs and move into better jobs by providing critical job retention and support services. In addition, we need to focus more on fathers, to ensure that every State helps committed fathers fulfill their basic obligations to their children on welfare. Many fathers want to do the right thing, but do not have the skills to earn enough to meet their child support responsibilities.

The challenge of closing the skills gap is central to this country's ability to compete in the 21st Century. By closing the skills gap, we can help close the wage and benefits gap, as well. We must offer low-skilled workers the opportunities to find and sustain productive employment with career potential.

For the Bureau of Labor Statistics (BLS), I am requesting $22 million to improve statistical indicators which are essential to the development of economic policy and the ability of businesses, labor and governments to make well informed decisions. This includes resources to augment the Employment Cost Index (ECI) with an addition of 7,000 establishment units to its sample. The ECI, as you know, is the Principal Federal Economic Indicator that provides the nation's most comprehensive

measure of changes in employer costs for all compensation (including wages, salaries and employer provided benefits).

To expand the application of quality adjustment and accelerate the introduction of new products for rapidly changing industries in the Producer Price Index (PPI), extend PPI coverage for the first time in the construction sector of the economy, to enhance the ongoing expansion of PPI coverage of the service sector, and to improve our productivity measures, I am requesting $5.1 million.

These funds also include a request for resources to continue the multi-year Consumer Price Index (CPI) Improvement Initiative effort begun in 1998 to improve the timeliness and accuracy of the CPI. This is the third year of the expansion effort to speed the process of updating the expenditure weights in the CPI Market Basket and to expand the amount of information collected on prices and characteristics of certain goods and services.

We will continue streamlining and begin a major restructuring of immigration activities by transferring the Alien Labor Certification Program from ETA to the Employment Standards Administration (ESA). This effort is consistent with the recommendations made by the Commission on Immigration Reform (CIR) as outlined in its report "Becoming An American: Immigration and Immigrant Policy" in September 1997. In addition to the consolidation, ESA will reengineer the program to better serve the customers of these programs while enhancing the Department's ability to effectively protect foreign and similarly employed U.S. workers.

These programs will help ensure that the workforce of the 21st century is ready to tackle the challenges ahead. We must prepare our workers to seize the opportunities presented by the expanding global economy, while at the same time we must preserve and expand the economic security of working Americans and their families.

This brings me to my second strategic goal: ensuring a secure workforce. We know that more Americans are working than ever, and they are bringing home higher earnings as well. This is real progress. Still—additional challenges lay ahead of us.

Closing the benefits gap

As I pointed out earlier, research conducted by the Department of Labor shows that the disparity in benefits such as health insurance and pension coverage between low-wage workers and highly skilled workers continues to grow. Less than half the workforce is covered by an employer-sponsored pension plan. And the percentage of the workforce covered by private health insurance is dropping—more than one in four workers has no employer-provided health coverage. Bureau of Labor Statistics research shows that the decline is even worse for low-wage workers. The wage gap is increasingly becoming a benefits gap as well.

My budget has several proposals which are designed to address this issue by providing workers access to information on benefits, such as health care and pensions, and also for employers, particularly small businesses, to help them meet the needs of the changing workplace. We can and must do better. We must protect the benefits earned by so many working Americans, while we also expand coverage to the many who lack access to these needed programs.

Pension security and health care initiatives

American workers deserve a secure retirement. Social Security is an integral part of the retirement equation, and we must do all we can to ensure that the benefits are there for our children and the generations yet to come. We should not spend the budget surplus until we save Social Security. The promises made to our workers and our children must be kept.

But all three legs of the retirement stool must be strong, so we must also help all Americans save for their retirement. I have long supported pension and savings education programs. All of you understand the importance of preparing for retirement.

The American people also understand the need to save, but many simply cannot afford to do so. In his State of the Union address, the President proposed an historic initiative—using 12 percent of the budget surplus to establish Universal Savings Accounts to give all Americans the opportunity to save. These USA Accounts will give every American a share in the wealth of this Nation, and help all to enjoy a more secure retirement. I am committed to making USA Accounts a reality this year, and I look forward to working with the Congress on this essential program.

We must also strengthen and promote the security of the private pension and health systems. My budget includes $11.8 million over last year for enhanced pension security and health care initiatives. The Pension and Welfare Benefits Administration (PWBA) will provide education and outreach to American workers and their families to make informed decisions about how to best protect themselves from being financially overburdened by the cost of day to day medical expenses or a cata-

strophic illness. PWBA has stepped up its efforts in regulation, enforcement and disclosure especially with respect to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). PWBA's role is also expected to increase with enactment of legislation currently under consideration by Congress such as the Patients' Bill of Rights and genetic nondiscrimination legislation.

My request includes an increase of $5.0 million for the final installment of a multi-year effort to improve reporting and processing of Form 5500—Annual Reports on employee benefit plans in the new ERISA Filing Acceptance System (EFAST). Funding is also included to improve the Internet site, which would disclose images of the most recent Form 5500 annual reports for approximately 800,000 health and pension plans. The new system which will begin operation in July, 2000, will improve the quality and accuracy of data, and will speed their use in safeguarding pensions. These reports provide financial information and answers to questions designed to highlight possible problem situations regarding the safeguarding of plan assets.

I am also requesting $2.6 million for PWBA's Reporting Compliance Enforcement activities and Customer Services initiatives.

To develop new ERISA data sources on covered employee benefit plans and to conduct research and policy analysis required to address emerging policy, legislative and operational issues, my budget includes $1.4 million.

Related to our pension protection initiatives, I am also requesting $1.5 million for the Office of Inspector General. These funds will be used to target the industry of service providers and seek to prosecute individuals who pillage pension plans causing financial hardship for workers or retirees.

I have made pension security a top priority—especially for women. Last fall, the President released a report demonstrating that women rely especially heavily on Social Security and lag in private pensions. In response, we are proposing two initiatives to help women in their retirement. First, we will require that pension plans that currently must offer joint and survivor annuities must now offer options ensuring that a spouse—usually the wife—does not experience a steep decline in pension benefits after the death of the husband. This will not increase costs to the plan. Instead, the couple can choose to receive a slightly lower benefit during their lives, in exchange for increased income for the survivor.

Second, we should require pension plans to count any time used under the Family and Medical Leave Act toward pension vesting and participation requirements. This will help ensure that working family members—again, mostly women—need not sacrifice their pension in order to take time off to care for a new baby or seriously ill relative.

These modest proposals will help ensure that millions of older Americans, especially women, can live in dignity.

Mr. Chairman, as you, and many others on the Committee know so well, too many Americans have no access to a private pension. That is why we are proposing measures to increase coverage and portability. We want to improve the rules so that more employees can take their pension benefits with them when they change jobs. We should make it easier for small businesses to establish pension plans, especially plans that give workers predictable, guaranteed pensions. Finally, we want to enhance the private pension rules to help keep employees' pensions safe. These and other measures can widen access to the private pension system and make it more secure. That is a goal we can all support, and I will do all I can to see that these proposals are enacted in this Congress.

One of my top priorities involves ensuring access to health care for millions of Americans with disabilities. Last year, we established the Presidential Task Force on Employment of Adults with Disabilities, which I chair. Our Task Force has already made tremendous progress in bringing together government agencies and identifying real solutions to help people with disabilities find real jobs. But we must do more. Mr. Chairman, the President and I strongly support the notion that millions of Americans with disabilities can and want to work, yet cannot afford to give up their health care to do so. We should break down the barriers keeping these Americans out of the workforce. No one should be forced to choose between keeping his or her health care and taking a job.

Like many on this Committee and across the Nation, I am also concerned about the quality of health care. American workers and their families deserve the world's best health care. The managed care system has dramatically altered the delivery of health care in America, coupling lower expense with an emphasis on promoting health instead of merely treating illness. We all believe in cutting costs, but not at the expense of quality. Within the Department, we are developing regulations ensuring fair treatment for people when employer health plans deny or delay promised benefits. But many important patient protections can only be achieved by improving

Federal law. That is why the President and I are committed to a strong and enforceable Patients' Bill of Rights. I look forward to working on this vital issue with this Congress.

Other security initiatives

To make sure we leave no one behind, the President's budget includes an initiative to strengthen the Unemployment Insurance (UI) safety net to make the program more accessible to unemployed workers, assure the availability of benefits in the event of an economic downturn and improve State administrative operations. In addition, we want to have further discussions with stakeholders and the Congress to develop broader bipartisan reforms to the unemployment compensation system, consistent with budgetary constraints. Our goals are to expand coverage and eligibility for benefits, streamline employer tax filing and reduce tax burden where possible, emphasize reemployment, guard against abuse, and improve administration.

For the Unemployment Trust Fund (UTF), I am requesting increases of $71 million to invest in integrity activities such as benefit payment control, screening for eligibility for benefits, and field tax audits. These functions are vital for benefit payment accuracy, detection of overpayments (fraud and non-fraud), and collection of non-paid and under paid State taxes. Failure to provide an evenhanded, accurate and fair UI program results in losses in State tax funds, increased fraud, and error.

The Wage Record Initiative, for which I am requesting $40 million, will fund State Employment Security Agencies for the one time cost to increase computer capacity to accurately report needed information for each worker for the National Directory of New Hires. This initiative will permit the Social Security Administration to verify names and social security numbers and thus improve the usefulness of the data for Social Security and child support enforcement purposes.

To assist ETA in the efforts to preserve the integrity of the Unemployment Insurance Trust Funds, I am also requesting $1.2 million for the Office of Inspector General. These resources will support high impact criminal investigations to target and investigate schemes that might otherwise defraud the UI program.

And, we are proposing consolidation and reform of Trade Adjustment Assistance (TAA) and the NAFTA-Transitional Adjustment Assistance (NAFTA/TAA) programs and extension through September 30, 2001. The reforms will extend TAA eligibility to those who lose their jobs because of shifts in production abroad—similar to the current provision for workers who lose their jobs because of shifts in production to Canada or Mexico. The reforms will also increase the cap on training expenditures, harmonize the existing requirements linking training and income support, and provide supportive services as needed.

Closing the gap in working conditions

My final strategic goal is fostering quality workplaces that are safe, healthy and fair to help close the gap in working conditions. All American workers deserve safe worksites, healthy working conditions and fair pay. The benefits of these workplace enhancements flow to employers, too. Quality workplaces reduce turnover, which increases productivity. Employers see the results on the bottom line. So ensuring high-quality workplaces isn't just the right thing to do, it's in an employer's own best self-interest as well. I am also committed to improving working conditions abroad by aggressively working to eliminate abusive child labor and by promoting international core labor standards.

Low-wage workers often work in demanding jobs that are accompanied by difficult and sometimes dangerous working conditions. The risk of lost-time injury in low-paying jobs is higher than in jobs held by highly skilled wage earners with good fringe benefits. To help close this gap, I am focusing the Department of Labor's emphasis on enforcement and compliance assistance to ensure conformity with our regulatory programs.

International labor standards/child labor

We have also targeted abusive and exploitative child labor, both at home and abroad, through a comprehensive strategy of enforcement, education and partnership. But we can do more. I believe that in the new global economy, we have an opportunity to lift millions of people into a worldwide middle class and a decent standard of living without exploiting children. My fiscal year 2000 budget proposals attempt to harmonize the Administration's goals of increasing trade and improving working conditions. Promoting international core labor standards and improving worldwide enforcement of labor laws is vital to this effort. Achieving expanded opportunity and security for American workers has become increasingly dependent upon how effectively the U.S. addresses the international challenges of economic globalization.

Child labor

My budget request continues to provide $30 million for grants to enable the International Labor Organization to expand its work to eliminate abusive child labor in more countries and industries. This five year initiative, which began in 1999, will help ensure that goods produced abroad are not made with exploitative child labor. Senator Harkin, I want to thank you for your active leadership over the past six years in this important work.

International labor standards

I am asking for an additional $35 million in fiscal year 2000 to promote core labor standards throughout the world. This includes $25 million for a major new ILO-based multilateral program designed to help developing countries implement core labor standards and build their own social safety nets.

I am requesting an additional $10 million for DOL to provide technical assistance on these same issues in support of important U.S. bilateral relationships. Examples of the sorts of projects we are planning include training in occupational safety and health, local economic development, dislocated worker services and social insurance reform.

On the domestic front, ESA's Wage and Hour Division (Wage and Hour) will continue to pursue and expand our strategy of enforcement, education and partnerships by requesting an additional $4.25 million for this effort. We have a special focus on child labor compliance in agriculture, through our "Operation Salad Bowl" initiative, and the garment industry, through our "No Sweat" initiative. Wage and Hour is expanding its use of the "hot goods" remedy to deter those using illegal and abusive child labor—and their customers—from violating the law.

Last summer marked our third annual "Work Safe This Summer" educational campaign to give child labor compliance information directly to young workers, parents, educators and employers. We also renewed our "Fair Harvest/Safe Harvest" campaign, which educates farm workers and their children about workplace rights, child labor and safety/health hazards in agricultural employment. And, in December 1998, we added a child labor component to our "E-Laws" Internet Advisor. Now, young workers, parents, teachers and employers can log onto the Internet for comprehensive, easy-to-understand information about child labor protections.

Finally, we have established partnerships with commercial consumers of agricultural goods. H.J. Heinz, "Newman's Own" and others are working with us to help prevent abusive child labor. And we work directly with employers to help them comply with the law.

Safe and healthful working environments

We have made real progress in this area. The rate of occupational injuries and illnesses is at an all-time low. Thirty years ago Congress passed two landmark pieces of legislation that together help ensure a safe and healthful workplace to all working Americans. Since then, the Mine Safety and Health Administration, working in partnership with the mining community, has made dramatic improvements in miners' safety and health. Last year, the number of mining-related deaths was the lowest in history. This is real progress. But one death, one disability, one case of black lung is one too many. There is still more to do.

Safety and health

The Occupational Safety and Health Administration has achieved comparable results, helping to save millions of American workers from illness and injuries on the job in industries ranging from construction to manufacturing to service and retail firms. In the coming year, OSHA will continue its effort to enhance partnerships with employers. We know that most employers want to do the right thing, but many need help to do so. I am committed to enhancing our partnership efforts through compliance assistance, consultation programs, and other cooperative mechanisms. However, we must retain a strong enforcement capacity as well, to protect workers against those employers who simply refuse to comply with the law. And, we will continue our work on a standard to help employers prevent the onset of debilitating work-related musculoskeletal disorders.

A high priority this year is the development and issuance of a proposed ergonomics program standard. There were 647,000 lost-workday musculoskeletal disorders reported in 1996, which accounted for approximately one-third of all injuries and illnesses that year that resulted in one or more days away from work. Work-related musculoskeletal disorders account for $1 of every $3 spent for workers' compensation and cost $15–20 billion in workers' compensation costs each year. An enormous body of scientific evidence demonstrates a clear relationship between work and the onset of musculoskeletal disorders. In addition, many companies are

successfully implementing ergonomic programs, protecting their workers, and achieving significant savings. OSHA has spent the last several years talking to hundreds of business people who have responded to problems by implementing successful ergonomic programs in their workplaces. Clearly, as so many employers, workers and scientists have already learned, ergonomics programs work. The draft ergonomics proposal OSHA released last month incorporates the basic features of ergonomics programs already used by many businesses to reduce their musculoskeletal injuries/illnesses.

I am requesting an increase of $35.1 million for workplace safety and health programs covering both compliance assistance and targeted enforcement. Included in my request is $10.5 million to enhance OSHA's compliance assistance activities by providing staff in every Federal OSHA office that will be responsible for direct outreach and training assistance to employers, and by providing for an increase in the number of training grants and expert advisors.

For targeted enforcement activities, my budget includes increases of $4 million to focus front-line efforts on the most dangerous workplaces and hazards. Over the past several years, OSHA has undertaken measures to leverage its resources and utilize information to target firms with the highest workplace injury rates. With information generated from the data initiative, OSHA has been able to identify those employers with the worst safety and health programs and direct resources to those work sites.

I am requesting an increase of $13 million for Mine Safety and Health programs. This includes $2 million to conduct more frequent dust sampling, target operator abatement activities, enhance MSHA's ability to maintain and calibrate sampling and laboratory equipment, and to process the additional dust samples collected. This proposal builds on fiscal year 1998 and fiscal year 1999 efforts—it is the third year in our program to eliminate black lung disease. Resources are also included to reduce fatalities among metal and nonmetal miners. There are more than 11,000 metal and nonmetal mines throughout the country, ranging from very small sand and gravel operations to large, open pit copper mines. As a result of the Transportation Equity Act for the 21st Century and the continued growth of our nation's economy, we have already seen increased activity in the aggregates industries. The need for more education and training has never been greater.

More than 20 years ago, when the Mine Act was passed and signed into law, the Congress and Administration wisely decided that education and training were critical elements of an effective safety and health program. As a result, we are now actively engaged in a results-oriented dialogue to come up with final training rules for the men and women who work in some 10,000 surface nonmetal mines. We are on course to promulgate these rules that are so critical to our continued success in protecting miners' safety and health.

Family and medical leave (FMLA)

The Family and Medical Leave Act allows workers to take up to 12 weeks of job-protected, unpaid leave to care for a newborn or adopted child, attend to their own serious health needs, or care for a seriously ill parent, child or spouse. The President is proposing to expand FMLA to businesses with 25 or more employees, and to allow FMLA eligible workers to take up to 24 hours of additional leave each year to meet family obligations. The budget includes $10 million for the Department to research the impact this law has had on the American family and how to make leave accessible and affordable for more of America's working families.

Equal pay/civil rights

We must also step up our efforts to end wage discrimination and expand employment opportunities for all working men and women. Today working women earn only about 75 cents on the dollar compared to men. Only part of this gap can be explained by differences in workers' education, experience, and occupational characteristics, and the rest appears to reflect persistent discrimination in pay. That is why the President's budget will invest $4 million for ESA's Office of Federal Contract Compliance Programs (OFCCP) under the President's Equal Pay Initiative to increase outreach, education, and technical assistance to Federal contractors. OFCCP will assist contractors by providing additional tools to assess current pay policies and practices and make any necessary improvements. OFCCP will partner with the Women's Bureau on a public education program on pay discrimination.

Let's be clear. This isn't simply a women's issue, it's a family issue. Today, nearly 3 out of 4 women with children work. And in 10 million families, women are the primary breadwinners. But it's hard to get by on three-quarters of a loaf of bread. I would like to thank Senator Harkin for his very important work in the area of ending wage discrimination. The President and I are committed to improving the

enforcement of wage discrimination laws and providing research, education, training and outreach on this important issue.

One stop services to workers and employers: Crosscutting initiatives

The Department's fiscal year 2000 budget submission is the product of a new and rigorous process, driven by an unusually high level of interagency cooperation throughout the Department. Given the complexities of the challenges now facing America's working families, I directed agencies to work together to develop, wherever possible, "crosscutting" initiatives that would bring all the necessary tools to bear on a problem. As a result, the fiscal year 2000 budget includes proposals to pilot test several exciting and innovative approaches—more effective alternatives to the ways in which we have traditionally developed and implemented our programs. By unifying our efforts into proposals that transcend the traditional individual agency approach, I anticipate that we will make significant strides forward in our capacity to help serve the American worker better.

The Department's innovative one-stop system for employment and training, launched as an experimental program in the first years of this Administration, has now become a national system that provides one-stop assistance on all employment and training related needs.

Crosscut: Worker education and outreach

For example, I am requesting $6 million to add information services on a full range of DOL programs and regulatory requirements to the existing information and outreach currently available to American workers and employers. DOL will partner with State employment offices to pilot test a network of 50 one-stop walk-in centers for information on the full range of DOL assistance programs and workplace regulations. The Department would offer information for workers on employment and training programs, job search and training opportunities. Employers and individuals seeking employment will have available in one location, information about compliance assistance, pensions, health care, safety and health standards, minimum wage requirements, and child labor rules. No one should leave these centers confused about their rights or obligations.

Crosscut: Coordinated compliance assistance for business

I am requesting an increase of $2.6 million for a Coordinated Compliance Assistance for Business program. To meet the needs of the changing workplace, where more small and medium-sized businesses lack the resources of many larger businesses, the Office of Small Business Programs (OSBP) would develop, implement, manage and evaluate the Department's new Coordinated Compliance Assistance pilot project for small businesses. OSBP would staff help desks at ten sites in three regions, and would serve as point of contact for DOL information. Specifically, the pilot program would partner with Federal agencies, and other organizations such as Small Business Development Centers, Agricultural Extension Offices, and Manufacturing Extension Partnership Centers to increase the availability of DOL information through on-site services in their existing education and assistance facilities. For example, OSHA would expand the development of education and training materials, and PWBA would make available products designed to inform businesses that offer pensions or health care benefits of the legal requirements of these benefits.

My request includes an increase of $1.875 million for a cross cutting initiative we refer to as Technology for Excellent Customer Service (TECS). The Wage and Hour Division would pilot test a Department-wide integrated information technology system to provide workers, employers, including small business, with prompt identification and referral to their specific requests and areas of need. We would be able to centrally handle and route a large volume of phone calls seeking information to the appropriate DOL agency.

Crosscut: Innovative enforcement

My request includes $1.7 million for Alternative Dispute Resolution (ADR). While a strong enforcement program is essential to ensure compliance with our workplace laws, the Department cannot rely entirely on traditional means to comprehensively enforce the labor laws for which it is responsible. Innovative methods are being developed for working with employers to make maximum use of resources. In some cases, alternative methods of dispute resolution can resolve cases and avoid expensive litigation costs, for example, ADR can resolve problems with employers by clearing up inadvertent fiduciary violations in their health and benefit plans. The Department is currently participating in efforts at the Department of Justice to develop prototype ADR programs.

Finally, we will work more closely with the Department of Justice to enhance criminal enforcement by targeting resources on the most serious violators of the labor laws that we administer.

Crosscut: Strategic management

In addition to these program proposals that cut across agency lines, I am also requesting funds for three management crosscuts that are vital to the successful design, development and operation of all departmental programs. In fiscal year 2000, I am asking for a total of $41 million to enhance the Department's efforts in the areas of information technology, financial management, and performance measurement. These management cross cuts allow the Department to tackle common problems across agencies in a cohesive and consistent manner.

In the information technology arena, I am requesting several program increases totaling $30.7 million to ensure that the Department meets the legislative mandates of the Clinger-Cohen Act, Paperwork Reduction Act, Computer Security Act, Year 2000 challenge and the Administration's policy on the management of information resources and technology within the Department. These resources will allow the Department to meet the increasing demands for Web Services across program agencies, provide greater electronic access to DOL information and materials, and continue implementation of the Department's common IT and Web architecture.

On the increasingly important Y2K issue—we expect all DOL systems to be Year 2000 compliant by the Government-wide deadline of March 31, 1999. The Department has a total of 61 systems considered critical to our mission to serve American workers. As of February 12, 1999, 52 of these systems had been renovated or replaced to correct Year 2000 problems.

After the completion of system repairs or replacement, we are requiring each mission critical system to undergo a rigorous assessment of Year 2000 readiness performed by independent reviewers, to provide further assurance that the Department's systems will effectively transition into the next century. This assessment program, referred to as Independent Verification and Validation (IV&V), is scheduled to be completed by June 30, 1999.

Notwithstanding our efforts, we recognize the potential that unanticipated problems or circumstances beyond our control could cause system or operational failures in the Year 2000. We are developing Business Continuity and Contingency Plans to ensure the continuation of all mission critical services and operations and will test these plans during 1999.

The Department has also provided guidance and technical assistance to our program partners, such as State and local government agencies and private sector organizations, in preparing for the Year 2000 and ensuring the uninterrupted delivery of benefits and services to America's workers. To effectively implement the Government Performance and Results Act enhancements (GPRA), I am requesting a total of $7.5 million to undertake initiatives on behalf of several agencies to enable them to increase their capacity to become results-oriented performance based organizations. I am requesting resources for several agencies in the areas of performance measurement development; expanding data capacity to establish baselines and collect data for the measurement of outcomes; establish procedures for assuring the validity and reliability of data systems to support performance measurement effort and the requirement to conduct program evaluation to periodically assess the effectiveness of programs and strategies to achieve the statutory purpose of the Department's programs and activities.

In addition, my budget includes several increases totaling $2.8 million to support Financial Management activities with several agencies. These increases will enable the Office of Inspector General to meet increased financial management audit responsibilities, and will help ETA to closeout JTPA grants timely and accurately.

I am sure you will agree that initiatives related to GPRA implementation, improvements in financial management and information technology investments are an integral part of any serious efforts to manage for results.

CONCLUSION

I am delighted to have had this opportunity to discuss my fiscal year 2000 budget request with this distinguished panel. The ideas, policies and programs embodied within this request, I believe, will benefit our country by looking after our most precious natural resource—the lives of our workers and their families.

I look forward to working with the committee and I thank you for the opportunity to appear before you. I will be happy to respond to any questions.

STATUS OF WELFARE-TO-WORK

Senator SPECTER. Thank you very much, Madam Secretary.

The $1 billion in the Welfare to Work Jobs Program is included in the budget this year. I would like your evaluation as to how well welfare reform is working. We have from time to time sharp concerns expressed by people like Philadelphia's Mayor, Ed Randall, about the adequacy of job opportunities for people. It is one thing if a person turns down a job. It is another if a person cannot find a job.

As we have structured the welfare reform and have given some latitude to the States as to how it is implemented, what is your assessment? Are we going to have people falling through the cracks, who will be taken off of welfare under the limitations of the reform where jobs are realistically unavailable?

Secretary HERMAN. I think, in the main, Senator, the overall efforts to reform welfare, as we know it, have worked. I believe that we are partnering effectively with State governments, with local workforce delivery systems, to meet the demand of both the training and the placement of welfare recipients who are making that transition.

This being said, I also recognize that we have key areas still in our country where there is clearly still a more disproportionate share, if you will, of those who remain on the welfare rolls who still have particular challenges. Those individuals clearly have multiple barriers, often, to employment. We need to have a more targeted approach, if you will, to work more closely with those communities.

Specifically, as you reference what is taking place in the State of Pennsylvania and in particular Mayor Randell of Philadelphia, there I recognize that we have had a more narrow definition, if you will, of the term "work activity," where we perhaps would have wanted to have more flexibility for being able to move welfare recipients into a broader array of job training opportunities and jobs themselves.

This is why I believe that the reauthorization of the Welfare to Work dollars is very, very important, because the TANF funds essentially are legislatively bound to the time limits. The Welfare to Work dollars are not.

We need to be able to target those dollars more aggressively, quite frankly, to where the need really is and to make sure that we are going to make greater investments in looking for training opportunities that lead to jobs and closer linkages with employers. In my own experience from being in the field, we need greater coordination now between those agencies that are providing those services in the local community.

I would just conclude by saying that, overall, it is working. It has been a work in progress. We are learning a lot. There are pockets where we have higher numbers who still remain, where we have to have a much more targeted and aggressive focus to give them the support services that they are going to need to become employable. I would identify the Philadelphia community as one of those areas.

FOCUSING ON THOSE MOST IN NEED

Senator SPECTER. Madam Secretary, you used the words "in the main," that the program is working "in the main."

To the extent that people do fall through the cracks, what is the answer, because I know you share my view that "in the main" is not really sufficient?

Secretary HERMAN. I do share your view on that.

Senator SPECTER. And, to the extent anyone falls through the cracks, we have to make an assessment. If they are turning down jobs, that is one thing. But if they cannot find a job, that is another. That assessment has to be made and there has to be assurance that people will not fall through the cracks.

Secretary HERMAN. And we are making those assessments. When I use the term "in the main," I am speaking more broadly of the experience factor. But this is not to say that where we find issues of individuals who are not perhaps getting the array of services that are available to them, we are not taking corrective action.

Specifically, what we are doing really is three things in that area. The first, as I indicated earlier, is to work for closer coordination of all of the service providers that have to support individuals who are making that transition today, from the Department of Health and Human Services, to the Agriculture Department, to the Departments of HUD and Labor. We have to have greater coordination so that individuals do not fall through the cracks.

We also are setting up a more aggressive case management system so that we can follow individuals and be more closely connected to their individual needs and what it is going to take.

Third, we are doing a better job of tracking those who are coming up against the time limits so that we will know exactly through our case management process what it is they are going to need, from training to child care, to transportation assistance.

Those are all of the more strategic steps that we have to take to make sure that no one, quite frankly, falls through the cracks and that everyone is able to benefit from the services that are, currently being, provided.

It also includes, in my view, a more aggressive outreach to the employer community so that we can continue to work for jobs in the private sector and to make the link to real jobs in the community.

Senator SPECTER. Madam Secretary, Senator Gorton attended the hearing but had to leave for other commitments. We are going to be submitting to you a series of questions from him. I want to make his questions a part of the record. They will be transmitted to you in due course.

UNIVERSAL RE-EMPLOYMENT

The proposal for the Universal Re-employment Initiative, working toward having every American have access to one-stop career centers, is an excellent idea.

How long do you think it will take before that program will be completed?

Secretary HERMAN. We estimate that it will take the next 4 to 5 years to make the investments to respond to the Universal Reemployment Initiative itself.

Senator SPECTER. Could that timeframe be expedited?

Secretary HERMAN. Well, it could be expedited if we had additional funding beyond what we have asked for in this budget. But it is also an issue of systems readiness.

As you know, Congress passed the historic Workforce Investment Act that requires us to reform all of our job training systems by July of 2000. We are in the process of doing that now and I expect that all of those systems will be on-line and that the consolidation and the reforms that have been mandated will, in fact, be in place.

It is then building on that infrastructure, as well, in the outyears that we would want to point to. But I would expect that we could reduce the timeframe with additional resources earlier rather than later.

ASSISTANCE TO AT-RISK YOUTH

Senator SPECTER. I think that would be useful if that could be expedited.

I note the Youth Opportunity Grants to reduce unemployment among youth in high poverty areas. The $250 million current level is going to be maintained.

This is certainly a very, very sensitive area which impacts on so many lives, not only in employment but crime, welfare costs, et cetera.

I know we could be doing more. Is it realistic to have more resources applied there in terms of a benefits ratio for the cost?

Secretary HERMAN. I believe that it is realistic to look at some additional resources. We do have a request in this budget that speaks to the Youth Right Track Partnership, which, in my view, is really a complement to the Out of School Youth Initiative that you funded last year.

To me, it is the flip side of the coin of the Out of School Youth Initiative because there, as you know, the focus is on out of school youth. We have 15 million of those that we have so identified. Seventy percent of them are high school drop-outs.

The Right Track Partnership Initiative is basically designed as a pilot with WIA to take a preventive step, to ask ourselves can we prevent these kids from dropping out of school in the first place. And if we have a more holistic strategy that follows them early in their educational experience in high school, particularly in junior and senior years, when we now know from the evidence they are more prone to drop out of school, we can then prevent them from becoming, in fact, one of the out of school youth statistics that we are focused on in the $250 million?

So I see it as a complementary effort that gives us a more holistic approach to the whole youth focus. That, coupled with your interest and the support that you have given us as well on the special initiative that we are doing for youth offenders, gives us, in my view, a much more aggressive approach to all of the issues that our young people face today, particularly those who are most vulnerable to dropping out, to crime in our communities and who, quite

frankly, have very difficult issues attaching, or reattaching, to the labor market.

ARGUS LEARNING FOR LIVING

Senator SPECTER. Madam Secretary, earlier this month I was visited by a group concerning the Argus Learning for Living Program with former Oklahoma Senator Fred Harris. I had written to you about this subject, on a program which has provided live skills training, remedial education and job training in the South Bronx. That group seeks to expand in the Philadelphia area.

Are you in a position at the moment to give me your evaluation on how this program has worked in the South Bronx and whether you think it would be a good idea to expand it, say, in South Philadelphia?

Secretary HERMAN. I did have the opportunity upon receipt of your letter, Senator, to look into the program. I think the kinds of services that they are providing, the population that they are targeting, very much fits with what we are trying to do more broadly now under the Out of School Youth Initiative. We plan to be in touch with Senator Harris and the organization to inform them of the competitive grants that will be announced in April. We would encourage them to participate in a proposal submission to the Department as a part of that activity.

Senator SPECTER. I misspoke. It is the South Bronx. It is not South Philadelphia. That is an egregious area—error. It is not an egregious area. That was not a Freudian slip—unless it may be the South Bronx. Certainly South Philadelphia is not an egregious area. [Laughter.]

But I do not limit their interest just to South Philadelphia but to Philadelphia generally.

ERGONOMICS

Madam Secretary, of course, you know South Philadelphia, at least to some extent because you visited a training project there. You very graciously did so.

Let me ask you about the ergonomics issue. This has been a highly, highly contentious matter with the regulations being delayed. There have been draft regulations promulgated by the Department.

How important is it, in your judgment, to move ahead on the ergonomics Department of Labor program?

Secretary HERMAN. I think it is very important, Senator. When you look overall at the injury and illness rates in terms of what is now reported, we know that this is the area that has the highest incidence—approximately 34 percent each year—all lost-time injuries and illnesses.

I think that we have had a preponderance of evidence that suggests to us not only is there a scientific basis to proceed, based on the NIOSH study and the National Academy of Sciences study, which conclude that there is a link here, to the practical experiences of employers who have actually implemented these kinds of programs in their workplaces. They tell us not only does it reduce compensation costs just from bottom-line benefits, but that it has also led to increased productivity in their workplaces.

The other factor that we have learned from experience, from talking to employers who are following through on implementing ergoinitiatives in their workplaces, is that musculoskeletal disorders are preventable. It seems to me, after 20 years of debating this subject as to whether or not we should do it, it is high time we get on with how we do it, learning from best practices, learning from employers who tell us that this has been good for their workplace, for their workers, and for their bottom line.

Senator SPECTER. Madam Secretary, we have a number of questions which we are going to submit to you for the record. The issue of homeless veterans is one of enormous importance. Your budget includes $5 million for the Homeless Veterans Reintegration Program. It is an increase over the $3 million, but far short of the $10 million authorized.

The National Coalition for Homeless Veterans has estimated that 271,000-plus veterans are homeless on any given night.

Would you take a look at this program and see what might be done further to cover more veterans?

Also, there is a serious issue with respect to women trapped in poverty. A recent study by the Educational Testing Service found that women leaving welfare for work face many obstacles to obtaining highly paid jobs.

I would like for you to take a look at that and provide a response as to what might be done. Give your staff some opportunity to study that.

[The information follows:]

HOMELESS VETERANS REINTEGRATION PROJECT

Thank you for your support and we at the Department have worked hard to help as many homeless veterans as possible under the Homeless Veterans Reintegration Program HVRP.

The HVRP is a popular program with widespread support in the veterans' community. It is a successful and effective model that leverages resources available in the communities where it operates and thus enables finding homeless veterans jobs for less than $1,000 per participant and $2,000 a placement. The demonstration projects have effectively used linkages with both training and labor exchange entities for training and placement assistance and use their own community linkages to obtain jobs for veterans who are homeless as well. Cumulatively, from program year 1989 to 1994, these projects served 19,516 veterans and placed 9,808 veterans who were homeless, with a total funding of $19 million. In program year 1994, with a total of $5.5 million, the program served 7,432 and placed 4,017 homeless veterans.

Encouragement to address this problem is found in the local communities. The Veterans' Employment and Training Service's VETS recent solicitation for grant application to operate the HVRP program drew 53 applications for funding of which 18 urban and four rural areas received funding. The $3 million provided for fiscal year 1998 is expected to help more than 2,100 homeless veterans into jobs.

Funding fiscal year 2000 at the $5 million level will enable VETS to leverage VA and HUD program resources and increase efficiency of the program by enabling economies of scale for those communities with large numbers of veterans who are homeless. At this funding level, we estimate that more than 6,000 homeless veterans would be enrolled in programs and more than 3,500 would be placed in jobs.

WOMEN LEAVING WELFARE FOR WORK

We have just received the pre-publication draft of the executive summary of Educational Testing Service's study. We will provide our response to the Committee once we have had the opportunity to examine this draft.

UNEMPLOYED STEEL WORKERS

Senator SPECTER. The issue of the unemployed steel workers is one of overwhelming importance. I deferred this hearing because the Finance Committee had a hearing and I testified at 9:30 this morning. There is much that needs to be done structurally to change our trade laws dealing with dumping. But we need to have a more activist response for the steelworkers who are losing their jobs.

I would like for you to take a look at that, if you would, and perhaps, or specifically, ask the people in your department who cover Pennsylvania, West Virginia, Ohio, Indiana, and Illinois to take a look at what might be done by way of job training or some emergency assistance for the steelworkers. It will be a long time before we are able really to eliminate the dumping, even if we do it promptly. So we need to have some first aid for the steelworkers who have lost their jobs.

We appreciate your taking a look at that and submitting a report to the subcommittee about what further might be done.

[The information follows:]

OPTIONS FOR ASSISTING DISPLACED STEELWORKERS

The Dislocated Worker Unit and the Rapid Response Team(s) in each State provide the best mechanism for proactive contacts with employers who may be facing the prospect of worker layoffs in the steel industry. The dislocated worker reemployment system can do outreach and make early intervention contact with potential and actual dislocated workers through the following mechanisms:

Rapid Response contacts are made by the State Dislocated Worker Units (DWUs) with the steel company employers and affected workers upon receipt of information that there will be a layoff at an employer facility. WARN notices received by the State are a primary information notice for triggering the Rapid Response. In addition, State DWUs can forge contacts with steel industry employers in their State in order to be apprised of any future or potential layoffs. Finally, information obtained through various sources, such as the media, Chambers of Commerce, and employer contacts, can provide information that can trigger Rapid Response.

A Worker Profiling and Reemployment Services mechanism exists in each State to determine which IU claimants are likely to exhaust their UI benefits before obtaining new employment and, therefore are in need of reemployment assistance.

Petitions for Trade Adjustment Assistance (TAA), which are submitted to DOL, may be submitted by the employer, a union representing the affected workforce, or any group of three or more affected workers. Information regarding the procedures for submitting a petition are discussed at Rapid Response site visits, and are also include on DOL/ETA's Internet Web site. DOL is prepared to work through the workforce system to conduct outreach to worker groups upon notification of imminent layoffs to provide them with information and technical assistance with filing TAA petitions.

ETA will continue to process petitions filed on behalf of steelworkers in a timely manner, and will issue determinations within 60 days of receipt of petitions.

At the national level, the Secretary could meet with the heads of the steel companies to ask for their cooperation in letting the workforce development system know as far ahead as possible of layoffs, whether permanent or temporary, and when temporary layoffs become permanent. This will help in planning for the response to these actions.

Another national level action could be to get the steel companies to agree to use a certain percentage of their revenue for retraining their workforce.

It is important that the TAA program continue to focus on worker readjustment through retraining and that, only in instances in which training is determined not feasible or appropriate including instances in which there is a strong indiction that workers will be recalled by their former employer—should waivers from training be considered.

In instances in which it appears unlikely that workers will be recalled by their former employer, ETA will collaborate with States in which steelworkers are certified to encourage the enrollment of displaced steelworkers in TAA-funded retain-

ing. Further, with respect to workers subject to recall, ETA will support enrollment in training for those displaced workers who prefer retaining to recall. ETA will not object, however, to the granting of waivers from training for workers who are subject to recall by their former employers but prefer recall rather than retraining.

ETA will collaborate with States to ensure that State officials are knowledgeable of Short-Time Compensation (STC) programs—commonly known as work sharing. These programs provide partial unemployment insurance benefits to individuals whose work hours are reduced from full-time to part-time on the same job.

WORKING CONDITIONS FOR AMISH YOUTH

Senator SPECTER. Let me now move to an issue which is Pennsylvanian. I appreciate your calling me about this issue. I had written to you concerning the Amish Youth to Work in Supervised Vocational Settings and the Amish sawmills, a bill which was passed by the House of Representatives. It is one where I am hopeful that we can work this out by having your experts come up with a regulatory system which will accommodate the interests.

Many of the Amish young people do not go beyond age 14 in their education. This has overtones of First Amendment/Freedom of Religion issues. There are concerns about the safety in the sawmills.

Of course, you and I discussed this yesterday and you raised the very good question is there any innovative thinking which can solve this issue. We talked about the possibility of your visiting the sawmill, as I did.

I believe that there can be a program worked out consistent with safety for 14 year olds and to accommodate an interest. Numerically, this is not large, but you don't have to have a large number of people to have a problem in America which needs to be addressed.

Do you have any generalized thinking on the subject? I know you are prepared. I don't want to put any words in your mouth and you can come to Pennsylvania, as you have in the past, to look at our issues.

What is your overall thinking on this issue?

Secretary HERMAN. Senator, obviously as I said to you yesterday, this is an area where I know the Department has spent quite a bit of time looking at what it is we could do administratively to meet the needs of the Amish community to have their young people work in the sawmills but yet, at the same time, not be in conflict with Federal child labor laws in this area.

Because this is an area, as you know, that is still a hazardous occupation which prevents children from working in this area. We have sought to entertain proposals from the community to see what it is we could do to make for a safer work environment.

The general conclusions from the on-site reviews that the staff conducted are that it is difficult to secure, if you will, the environment, not just in terms of equipment and machinery, but other issues, as well, related to the dust and the general environment itself.

At the end of it all, because I do believe that we have made real attempts to try to find a workable solution here, though to no avail, I have indicated to you that I would like to make a visit myself, to go with you to visit the sawmills, to see first hand what are the issues that are being raised. In this way I will be in a better posi-

tion to respond back to you and also to reverify or look anew at the issues that have been raised with our own team at the Department.

Senator SPECTER. I appreciate your study to date and your willingness to come and pay a visit. There is nothing like seeing it first-hand.

Well, we run a very efficient hearing, Madam Secretary, when I am the only Senator present—maybe not so efficient, but less inefficient, perhaps.

It is a very busy day in the Senate. We are finishing up the Supplemental Appropriations Bill. We are about to begin work on the budget resolution. We have on the floor the issue of Kosovo. Every Senator has so many commitments and everybody on this committee virtually chairs another subcommittee of Appropriations.

But I know there is a very deep interest in the work of your department, and we will pay close attention to your budget request.

Thank you.

Secretary HERMAN. Thank you very much, Senator.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. Thank you very much. There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

LABOR'S EFFORTS TO DEVELOP ELECTRONIC REPORTING AND A PUBLICLY ACCESSIBLE DATABASE UNDER THE LABOR-MANAGEMENT REPORTING AND DISCLOSURE ACT

Question. The Employment Standards Administration of the Department of Labor administers numerous laws including the Labor-Management Reporting and Disclosure Act (LMRDA). The House Appropriations Committee is concerned about the difficulty the public has obtaining full and complete information on the reports filed under this Act. Therefore, in its July 1997 report, the committee recommended an appropriation of $500,000 in Labor's fiscal year 1998 appropriations to begin the development and implementation of an electronic reporting and disclosure system that could be easily accessed by the public through the Internet. The Congress appropriated these funds in fiscal year 1998 to begin the project. What is the status of the project?

Answer. Good progress is being made on all phases of this project. ESA is advancing computer programming required for new reports receipt and processing systems and the computerized audit program. A contract has been initiated with the National Technical Information Service (NTIS), U.S. Department of Commerce, to obtain recommendations and cost estimates for an Internet-based electronic filing and public disclosure system based on requirements developed by the agency. An additional contract to develop and implement electronic filing and disclosure is planned for this fiscal year based on those recommendations. Additionally, a contract has been initiated to advance plans for the conversion of information from paper-filed reports to electronic format for inclusion in the Internet public disclosure database.

With the additional $500,000 appropriated for this project in fiscal year 1999 and the $1 million enhancement requested this year, contract work on the Internet-based electronic filing, public disclosure, and audit systems can be undertaken ahead of the initial schedule. The agency plans to review and refine its planned project costs and timelines following careful review of contractor recommendations that are expected in April and will submit an updated plan to the Appropriations Committee.

Question. How did Labor spend the $500,000 initially appropriated for the project?

Answer. The $500,000 appropriated in fiscal year 1998 was obligated for contractor services. Contractor staff were employed to assist with technical aspects of the plan development and for development and planning of the new system.

Question. The House Appropriations Committee also directed that Labor submit a complete plan of implementation by April 1, 1998. Labor submitted a general plan in May 1998 and reported that the electronic system would be fully operational by the end of fiscal year 2001. What is the basis for your 3-year estimate to implement the system?

Answer. The project timeline in the May 1998 plan was based on careful consideration of a number of factors, including program requirements and information obtained in conferring with staff at other government agencies, firms with expertise in electronic forms design and document management technology, agency technology staff, and contractor staff employed for this project. The agency plans to review and refine its planned project costs and timelines following careful review of contractor recommendations that are expected in April.

Question. Based on the progress to date, is the 3-year estimate to implement the system still realistic? Would more funding allow you to implement the system sooner?

Answer. The agency plans to review and refine its planned project costs and timelines following careful review of contractor recommendations that are expected in April. The agency plans to submit an updated plan to the Appropriations Committee.

Question. You reported in the May 1998 implementation plan, that you expected to initiate contracts in the third quarter of fiscal year 1998 to develop the project. Why did you choose to use contractors to develop and implement the project and did you award contracts on a competitive basis?

Answer. Although agency staff resources are being used to work on program aspects of the electronic filing and disclosure system, contractors are needed to provide the necessary technological expertise for project development and implementation. Labor hours for system design work were initially secured under a contract authorized under Section 8(a) of the Small Business Act, not subject to full and open competition since the award price of the contract did not exceed $3,000,000. Starting on September 15, 1998, the labor hours for system design and programming work was obtained through Digital Equipment Corporation's GSA schedule. The agency contracted with the National Technical Information Service, U.S. Department of Commerce, for recommendations regarding the Web-based electronic filing and public disclosure systems. The NTIS was chosen based on its experience with other government agency projects. The agency has work underway with yet another contractor for a study regarding forms redesign to facilitate data conversion using OCR/ICR technology. The forms redesign study was not awarded competitively because it was for less than $10,000.

Question. Now that almost a year has passed since you submitted your original plan, do you expect to update the plan and provide copies of the updated plan to the Congress?

Answer. The agency plans to review and refine its planned project costs and timelines following careful review of contractor recommendations that are expected in April. The agency plans to submit an updated plan to the Appropriations Committee.

Question. Please elaborate on how your approach for developing Labor's electronic system compares with practices other government agencies have used to develop similar electronic systems.

Answer. Other agencies have electronic report submission systems such as will be established for the LMRDA report forms. The agency has consulted with numerous federal agencies regarding their systems. In general, we are following the same developmental approach and considering similar problems. The LMRDA reporting project, nevertheless, does have program-specific issues and concerns that need to be addressed, including the need to administer digital signatures for two signatories in each union and continual turnover in official signatories.

Question. In the House Appropriations Committee's July 1997 report, the Committee directed that Labor include in its future budget requests funds to continue the project. In the May 1998 implementation plan, Labor estimated the total costs of the electronic system to be $4.2 million. Based on your experience to date, is the $4.2 million still an accurate estimate for completing the project by fiscal year 2001?

Answer. The agency plans to refine its May 1998 project costs and timelines following careful review of contractor recommendations that are expected in April. An updated plan will be provided to the Appropriations Committee.

Question. In fiscal years 1998 and 1999, the Congress appropriated $1.5 million for the project. Your request for fiscal year 2000 is $1.0 million. Why would $1.7 be needed in the final year of the 3-year project?

Answer. The agency has not advanced a $1.7 million project cost estimate for fiscal year 2001. The May 1998 implementation plan did include a projected cost of $1.3 million in the final year of the project plan, primarily for development and implementation of the Internet-based reporting and disclosure systems. However, additional funds appropriated for this project in fiscal year 1999 and the $1 millionrequested fiscal year 2000 enhancement will permit work on the Internet-based system ahead of the initial plan schedule. The agency plans to refine cost and time projections following review of contractor recommendations and to provide an updated project plan to the Appropriations Committee.

Question. What is the status of your expenditure of funds to date?

Answer. To date approximately $900,000 has been obligated for contractor services. In fiscal year 1999 the remaining available resources, approximately $600,000, will be obligated for additional contractor services, including the design of electronic reporting forms, and the development of the electronic filing and disclosure systems.

EFFORTS TO REENGINEER THE DAVIS-BACON WAGE DETERMINATION PROCESS

Question. In its January 1999 report, GAO recommended several actions to reduce the cost of verification and increase the benefits. According to the report, you agreed to take action in response to these recommendations, including increasing the use of telephone verification, using a judgmental sample, and increasing efforts to obtain payroll documentation from all selected submitters. Please discuss the actions you are taking to implement these recommendations.

Answer. We are working very hard to assure that the Davis-Bacon wage data is accurate and that our processes for obtaining and verifying data are effective and efficient. Our progress on implementing GAO's recommendations is summarized below:

1. *GAO recommendation*.—Increase the use of telephone verification while decreasing on-site verification and increase efforts to obtain payroll documentation from all selected submitters. The sample of survey forms submitted by employers randomly selected for telephone verification will be increased (except where payroll data have already been submitted). We will continue to select a 10 percent sample of data collection forms from third party submitters for telephone verification. The telephone verification process will request documentation supporting the submission.

2. *GAO recommendation*.—Change the procedures used to select wage data for on-site verification, using a judgmental (rather than a random) sample of wage data submissions based on the potential impact of the data on prevailing wage rate determinations. The selected contractors will be contacted by telephone and asked to provide supporting documentation. If the documentation is not provided, the contractors will at least be sampled for on-site verification.

3. *GAO recommendation*.—Revise verification procedures to take more appropriate action when documentation cannot be readily obtained from a submitter, such as not using data when supporting documentation is requested but not provided, requiring documentation where possible, and giving third parties an opportunity to provide supporting documentation for data they submitted. Supporting documents will be requested in all telephone and on-site verification. If a submitter is not able or willing to provide documentation or access to the documentation, the data submitted may still be used unless the submitter has a history of not cooperating or has provided inaccurate data in the past. We are developing a system for tracking those that have previously failed to cooperate or provided inaccurate data. In addition, third parties will be given the opportunity to provide supporting documentation for all data they submitted.

Question. Despite the numerous errors found in submitted wage data by both Labor's OIG during fiscal year 1997 and on-site auditors during fiscal years 1998 and 1999, the revisions you made in the wage determinations were "minimal" in your estimation—less than 10 cents an hour. Why did these substantial errors in the wage data make such a small difference in the prevailing wage rate set using the data?

Answer. In the first place, the data errors found through our verification efforts in 1998 and 1999 (and previously) were not used in producing wage determinations; rather, these errors were corrected or eliminated through our verification process. Our verification procedures are intended and designed to correct or eliminate erroneous data, and prevent any attempt to systematically bias the wage/benefits data

reported. Nonetheless, verification cannot feasibly detect and correct all erroneous data.

There are a number of reasons why errors on survey data submissions would have little or no impact upon the resulting wage determination; the following examples illustrate why. First, however, it is important to note that neither the OIG review nor the on-site audits conducted by our verification contractor have found any evidence of fraud or other systematic efforts to bias the wage survey data. Some data submissions under-report and other submissions over-report what was actually paid. These errors tend to cancel each other, and the overall net effect is therefore minimal.

Examples of situations where errors in the data submission would have little impact on the resulting wage determination include:

1. A submitter reports ten electricians making $10.00 per hour. On-site verification determined that only two electricians were paid $10.00 per hour, but that three electricians were paid $8.00 per hour, two were paid $9.00 per hour, and three were paid $12.00 per hour. Calculating the absolute difference (i.e., not factoring in a plus or a minus for over- or under-reporting), would yield a average difference of $1.40 between the reported rate and the verified rates; however, the verified weighted average would be $9.80, a difference of only $.20 per hour from the reported $10.00 per hour rate.

2. A submitter reports paying carpenters $10.00 per hour in wages but reports no fringe benefits. On-site verification finds that the carpenters actually received benefits costing $1.50 per hour. The average fringe benefit payment for the other submitters who reported paying benefits was also $1.50 per hour. Under these circumstances, the failure to report fringe benefits would have no impact upon the resulting wage determination; however, the absolute difference between the reported and verified amount was $1.50 per hour.

3. The survey determines that 90 percent of the elevator constructors in a particular area are paid the same union rate. Under these circumstances, the current union rate is, by definition, the prevailing rate. One data submission form for work preformed last year reported that the elevator mechanics were paid today's union rate of $23.15 per hour when in fact the union rate last year was only $22.15 per hour. Thus, the absolute difference between the rate reported and the rate verified would be $1.00 per hour; however, the impact upon the wage determination would be zero because the reporting error does not alter the fact that the union rate prevails and the wage determination would be based upon the current union rate.

Question. You notified the Congress in 1997 that you had selected two options to test what you believed were the options most likely to improve the timeliness and accuracy of Davis-Bacon wage determinations. We would be interested in hearing more about the specific criteria you used to select these two options. What are these options and why were these considered the most appropriate means to increase timeliness and accuracy?

Answer. As we have advised the Congress, the Department considered a broad range of options before focusing its efforts and resources on two possible approaches: (1) using the Bureau of Labor Statistics' redesigned Occupational Employment Statistics (OES) survey as the primary basis for Davis-Bacon wage determinations, and (2) reengineering the current Davis-Bacon wage survey/determination process. These options were selected because they offered a significant opportunity to improve the timeliness and accuracy of Davis-Bacon wage determinations, and because they provided the opportunity for a complete solution. Some of the options initially considered only offered a partial solution. For example, utilizing State prevailing wage determinations would have been a viable approach only in those States that currently have a prevailing wage determination program of their own.

The Wage and Hour Division has established a long-term performance goal of being able to survey every area of the country for all four types of construction (residential, building, heavy and highway) no less often than once every three years, and to issue wage determinations that validly represent locally prevailing wages and benefits within 60 days of receipt of the underlying survey data. We believe that the two options currently being developed offer the best opportunity for achieving these goals.

WAGE DETERMINATION PERFORMANCE GOALS

Question. We are aware that you have developed two performance goals that you will use to gauge your success in improving the timeliness and accuracy of the wage determination process. Please explain how these goals will, in fact, ensure increased timeliness, accuracy and participation in the process. Also, please explain the proc-

ess and criteria Labor will use to develop these two specific goals and why you believe these goals would best indicate success.

Answer. The performance goals we have established for the Davis-Bacon wage survey/determination program under the Government Performance and Results Act are to:

1. Survey each area of the country for all four types of construction at least every three years, and the resulting wage determinations validly represent locally prevailing wages/benefits; and,

2. Update 90 percent of Davis-Bacon wage determinations within 60 days of receipt of the underlying survey data.

These performance goals focus specifically on timeliness and accuracy including frequency of data collection and the quality of the data collected. Wage determinations based on old data or erroneous data will not validly reflect locally-prevailing wage and fringe benefit rates. A timely wage determination is not acceptable unless it also accurately and appropriately represents locally prevailing wages and benefits.

For example, the use of OES data may not yield sufficient information to issue accurate rates for the different types of construction. OES may provide data for electricians in the construction industry as a whole in an area, but not for electricians in building, residential, heavy and highway construction, respectively. Clearly, a wage determination based upon data for the construction industry as a whole would be less accurate than a wage determination reflecting different types of construction. However, there may be other timeliness and accuracy considerations such as the frequency of data collection and the quality of the data collected that would compensate for using broader occupational data.

Participation directly correlates with accuracy but also affects timeliness. In both approaches we are pursuing, one of our goals is to increase participation without adversely affecting timeliness.

REENGINEERING WAGE DETERMINATION PROCESS

Question. Labor has been working on reengineering the wage determination process since 1996. What information is currently available that would document the progress you have made to date in improving the timeliness and accuracy of the wage determination process? Are there any results yet available from your efforts? If not, when would be the earliest that such results would be available and what would they be?

Answer. Pursuant to Congressional direction, the General Accounting Office (GAO) has been monitoring and evaluating our continuing efforts to reengineer and reinvent the Davis-Bacon wage survey/determination process. GAO will soon issue its initial report entitled, "Davis-Bacon Act: Labor's Actions Have Potential to Improve Accuracy and Timeliness of Wage Determinations." As indicated in the GAO's report, after examining a number of options, the Department concluded that the most promising approaches to achieving substantial improvements in the Davis-Bacon wage determination process are: (1) reengineering the current wage survey/determination system; or (2) using the Bureau of Labor Statistic's (BLS) redesigned Occupational Employment Statistics (OES) survey as the primary basis for Davis-Bacon wage determinations.

We believe that we have made significant progress on both approaches. During the last year, two BLS pilot surveys to determine the feasibility of collecting fringe benefit data have been completed, two more pilots have been authorized, and we are evaluating the potential usefulness of such data for determining prevailing fringe benefits. Additional OES data should soon be available for evaluation of the feasibility of using this wage data for Davis-Bacon wage determinations.

The Department has also implemented several reengineering initiatives, including a Statewide pilot survey in Oregon that uses new printing and mail processing applications and our new Davis-Bacon web site.

The following outlines progress on our reinvention and reengineering initiatives:

Reinvention initiative

During the past two years, Wage and Hour has worked closely with BLS to test the feasibility of utilizing BLS data sources as the underlying basis for future Davis-Bacon wage determinations. OES locality data for 1997 (⅔ of the full three year sample) will be available in the next few months, and Wage and Hour will continue to work with BLS to determine whether the two-thirds partial OES results will provide adequate data to produce locality estimates for the construction industry for evaluation. During fiscal year 1998, Wage and Hour funded an effort by BLS to test the feasibility of collecting data on union status by occupation as part of the OES data collection process. Based upon the favorable results of that test, Wage and Hour has contracted with BLS to begin testing actual data collection. BLS expects

to receive union data from the States by the end of August and begin analysis in September.

Because the OES survey does not provide data on fringe benefit Wage and Hour has worked with BLS to explore the possibility of utilizing National Compensation Survey (NCS) fringe benefit data to supplement OES. In fiscal year 1998, Wage and Hour funded (approximately $1.4 million) two pilot surveys (Jacksonville, FL, and Tucson, AZ) to collect detailed fringe benefit data for specific occupations in the construction industry. Both surveys provided considerable data for construction occupations and, based upon the results of these surveys, Wage and Hour has contracted with BLS to conduct two more pilot surveys in fiscal year 1999 in Toledo and Salt Lake City. Wage and Hour is analyzing the completed two BLS pilot surveys to evaluate whether and how these data might be utilized to establish prevailing fringe benefit determinations under the Davis-Bacon Act. Data from the second two BLS pilots will be available late this year. As a result, decisions on whether the NCS survey can provide a viable source of fringe benefit data for Davis-Bacon wage determinations can not be made until fiscal year 2000.

Reengineering initiative

The reengineering option builds on the current "universe" survey approach and seeks to use new technology and revised procedures to: promote greater survey participation; make the data collection and analysis process more efficient and less costly; and enhance our ability to verify data submissions. In addition to implementing new data verification procedures, recent accomplishments include:

—A redesigned data submission form (WD–10) that is machine-readable and more user-friendly. The form is in clearance and should be implemented in August 1999.

—A Davis-Bacon web site has been developed to provide information about the survey process, ongoing as well as planned surveys, and the (WD–10) data submission form.

—Standard business process modeling procedures have been utilized to model the survey process and identify opportunities for improvement.

—Knowledge Management tools—which can be used for survey data editing and evaluation—are being evaluated, and a selection will be made by the end of fiscal year 1999.

—The concept of surveying a broad geographic area for all four types of construction is being tested in Oregon (and in an upcoming Colorado survey), and a number of new technologies are being utilized. These include using multiple sources of survey universe data in electronic format, automated mailing of questionnaires and follow-up, automated data input eliminating manual input of 11,000 records, and respondent return tracking using bar codes. Reengineering efforts will continue over the next year. Additional improvements, such as new data input prototypes, additional internet information sources, and electronic imaging capabilities are being developed this fiscal year.

Question. Labor has decided to use existing BLS data collection systems as an alternative source of data under its reengineering process. You have identified the pros and cons of this option for the Congress. What issues would still need to be resolved in order to use BLS to collect wage and fringe benefit data as an alternative way to calculate and issue prevailing wage rate determinations?

Answer. The Department of Labor has not decided to use existing BLS data collection systems as an alternative source of data under its reengineering process. Rather, the Department is exploring and developing this approach, but no decision has yet been made as to how to proceed for the long-term.

The BLS Occupational Employment Statistics (OES) survey that we are considering as the possible source of wage data will not publish results based upon its full sample until sometime next fiscal year. Also, the results from all four National Compensation Survey (NCS) fringe benefit pilot surveys will not be available until next fiscal year. Thus, we are still at least a year away from being able to fully evaluate the BLS data and all of the issues affecting the possible use of these data as the principal source for Davis-Bacon wage determinations.

REQUIREMENTS OF MAJOR RULEMAKING INITIATIVES

Question. OSHA currently has two major rulemaking initiatives—the proposed ergonomics standard and a worksite safety and health program standard—that call for selected employers to create some form of internal worksite health and safety programs to protect employees from workplace hazards. Many employer groups are opposing both of these initiatives. California has its own ergonomics program standard and many state operated OSHA states have had worksite safety and health program standards for many years.

What kinds of duties would employers have in setting up worksite programs under each of these proposed standards and how would these standards differ?

Answer. The two programs are designed to work together. The safety and health program that would be required by that rule would establish the basic framework for managing all draft proposed safety and health issues in the workplace that are covered by OSHA standards or the General Duty Clause, while the draft ergonomics program rule would provide the specifics for addressing that hazard. The employer's ergonomics program would fit into the framework established by the safety and health program, since both programs contain most of the same core elements and are consistent with each other. The safety and health program rule would require employers to set up safety and health programs that include management leadership and employee participation, hazard identification and assessment, hazard prevention and control, information and training, and program evaluation, while the draft ergonomics standard spells out how each of these elements would work for ergonomic hazards. For example, the safety and health program rule would require employers to investigate accidents as part of their hazard identification activities, while the draft ergonomics rule would specify how to investigate and analyze the jobs that have led to musculoskeletal disorders (MSDs) in the workplace. In addition to specifying how employers are to implement each element of a safety and health program to address ergonomic hazards, the draft ergonomics rule would also require employers to set up a medical management program, a program element that is essential to achieve early reporting of MSDs but would not be required by the safety and health program rule.

Question. Which employers would have to set up programs under each of these standards separately and how many employers would have to set up separate worksite programs under both of these proposed regulations?

Answer. All employers in OSHA's jurisdiction in general industry would be required to set up a basic safety and health program under the draft safety and health program rule. Under the draft ergonomics rule, OSHA's preliminary estimates are that about one-third of these employers would need to establish a basic ergonomics program. Approximately two million employers would be able to incorporate an ergonomics program into the framework established by their safety and health program. No employer would be required by these draft rules to set up two separate worksite programs.

Question. Is it necessary to mandate separate programs through each of these standards to protect workers from workplace hazards?

Answer. Instead of writing rules that mandate separate programs, OSHA has drafted complementary program rules. If the agency finalizes both rules, covered employers will have a basic safety and health program in place that addresses all job-related hazards in their workplaces that are covered by OSHA standards and the General Duty Clause, while those employers whose employees work in jobs that have already caused an MSD or that have a high probability of doing so will have an ergonomics program that specifically addresses ergonomic hazards. OSHA believes that ergonomic hazards warrant their own rule because MSDs represent over one-third of all employer-reported workplace injuries and illnesses, because no existing OSHA rule addresses ergonomic hazards, because the workplace factors giving rise to MSDs are complex and multiplicative, and because the methods used to eliminate or control these factors are often unique to ergonomics.

EFFECTIVENESS OF ERGONOMICS AND SAFETY AND HEALTH PROGRAMS

Question. What evidence is available that suggests that ergonomics and general worksite safety and health programs would result in safer workplaces?

Answer. Workplace safety and health programs have been shown to reduce job-related injuries and illnesses in a wide variety of contexts. For example, four states that have had safety and health programs in place covering all employers in the state for a period of five years or more have achieved average reductions in reported injuries or illnesses of 17 percent above the national average for the same period. In addition, state workers' compensation programs in four different states that have required or encouraged certain employers to set up safety and health programs have observed declines in work-related injuries and illnesses of 10 to 20 percent per year among program participants, when compared with the injury and illness rate among non-participating employers in the state. Further, hundreds of thousands of employers across the United States have set up safety and health programs and ergonomic programs on their own and have found these programs to be highly effective in reducing injuries and illnesses, saving money, and improving employee morale and productivity.

With respect to ergonomics, there is evidence, based on success stories, of declines in musculoskeletal disorders of up to fifty percent and even greater reductions in workers compensation costs when ergonomics programs are established. As the agency proceeds with promulgation of an ergonomics standard, it will analyze additional data to support this evidence.

Question. What has been the state experience with both program standards regarding enforcement, administrative burden on employers and reducing workplace hazards generally?

Answer. Many states have mandated safety and health programs for certain groups of employers in the state, but only a few states require programs for most or all employers in the state. Those states that have programs for most or all employers have found them effective in reducing injuries and illnesses. Oregon, Washington, and California all consider their safety and health program requirements to be the centerpiece of their enforcement efforts. In these states, enforcement efforts focus first on encouraging employers to comply fully with the state's safety and health program requirements. There is little evidence on the costs or burdens of state program requirements. However, there is evidence in the state of Washington that compliance with the program requirements has been excellent, both for small and large firms.

WORKER PROTECTION PROGRAMS

Question. For Labor Department enforcement programs—worker safety, protecting pensions, health benefits, minimum wage and overtime requirements—you are requesting an increase of $129 million or 12 percent over the fiscal year 1999 level. What specific accomplishments do you expect to achieve with these added resources?

Answer. The $129 million increase in Worker Protection includes resources for the Pension and Welfare Benefits Administration (PWBA), the Employment Standards Administration (ESA), the Occupational Safety and Health Administration (OSHA), the Mine Safety and Health Administration, the Office of the Solicitor (SOL), and the Bureau of International Labor Affairs (ILAB). The requests for these agencies support two of my three goals for the Department: to ensure that all Americans are economically secure; and that all Americans are guaranteed a safe and healthful workplace with equal opportunity for all. The request for ILAB does not relate to domestic workplace enforcement, but does address certain workplace issues elsewhere.

One of the things we hope to achieve is to close the gap in benefits. Research conducted by the Department of Labor shows that the disparity in benefits such as health insurance and pension coverage between low-wage workers and highly skilled workers continues to grow. Less than half of the workforce is covered by an employer-sponsored pension plan. More than one in four workers has no employer-provided health coverage. BLS research shows that the gap is even worse for low-wage workers. Three-quarters of workers in small businesses are not covered by a pension plan. We must strengthen and promote security of the private pension and health systems. The wage gap is increasingly becoming a benefits gap as well. This budget has several proposals which are designed to address this by providing workers access to information on benefits, such as health care and pensions, and also for employers, particularly small businesses to help them meet the need of the changing workplace.

For PWBA, our request includes a net increase of $11.8 million for initiatives to enhance pension security and health care, of which an additional $8.2 million is requested for the enforcement and compliance activity. This request includes a one-time program increase of $5.0 million to offset the Department's share of the first year costs associated with processing Form 5500 Annual Reports for plan year 1999 in the new ERISA Filing Acceptance System (EFAST) in year 2000. The new EFAST system is projected to save the federal government $50.0 million over five years. This includes $1.2 million to be used to implement a proactive voluntary compliance program to facilitate corrections by fiduciaries who want to come in compliance with the law, which will promote better compliance in the future. Also included are $2.6 million to expand enforcement and customer service capacities related to the new health benefit laws covering private employers as well as to enhance health-related regulatory, interpretive analysis, and coordination activities. Another $2.7 million in program increases will be used to address emerging policy and legislative issues; conduct outreach programs to dislocated workers concerning their pension and health benefits and begin a pilot program on "one-stop" centers for education and outreach.

These initiatives are also aimed toward closing the gap in working conditions. The Department's intention is to foster quality workplaces that are safe, healthy and fair to help close this gap. All American workers deserve safe work sites, healthy working conditions and fair pay. The benefits of these workplace enhancements flow to employers too. Quality workplaces reduce turnover, which increases productivity. Employers see the results on the bottom line. So ensuring high-quality workplaces isn't just the right thing to do, it's in an employer's own best self-interest as well.

For ESA, our request includes the transfer of the Alien Labor Certification program from the Employment and Training Administration (ETA) to ESA's Wage Hour program. This transferred program renamed the Foreign Labor Certification Program by ESA includes $33.7 million and 98 FTE previously in ETA is part of the Department's plan to consolidate it's immigration activities as recommended by the President's Commission on Immigration Reform (CIR) in September 1997. In addition to the consolidation, the Department will launch a major restructuring of this program designed to streamline and create a fee-based, customer responsive program characterized by the timely processing of employer applications.

For ESA's Wage Hour program, we are requesting $4.3 million and 30 FTE to build on the domestic segment of the President's Child Labor initiative begun in fiscal year 1999 by increasing compliance efforts in targeted industries including agriculture and garment manufacturing, and other low-wage industries. This initiative will allow DOL to enhance efforts like "Operation Salad Bowl" and the "No Sweat" initiatives. We are also requesting an additional $700 thousand ($1 million is within the base) for the "Partnership with Service Providers" initiative, which will encourage voluntary compliance with Wage Hour laws through partnerships with organizations that provide services to workers and employers such as public schools and libraries, health care providers, and small businesses. We are also requesting $1.7 million to begin the Technology for Excellent Customer Service (TEC) initiative for a new computer-based telephone system that will allow the Wage Hour program to respond to approximately 5 million calls from the public on compliance issues.

Our request for MSHA is an increase of $13.1 million. This includes a $2 million increase for federal sampling of respirable coal mine dust and quartz, which will improve the timeliness of corrective actions to reduce the incidence of occupationally-caused lung disease among coal miners. The request also includes a $3.7 million increase to retool the metal and nonmetal safety and health program for reducing fatalities, injury incidence rates and miners' overexposure to health hazards. The request includes $3.0 million to provide increased educational assistance to the metal/nonmetal sector. The need for more education and training in this mining sector has never been greater.

Our request for OSHA includes a program increase of $25.6 million, with $10.5 million for Compliance Assistance Enhancement, committed to support the development and implementation of a comprehensive compliance assistance program. The program will bolster the agency's capacity to provide direct training and assistance to employers and workers to reduce injuries and illnesses on the job. For maintenance, replacement and investment costs associated with the agency's information technology infrastructure, the budget request includes $8.1 million. Another $4.0 million will be used to bolster resources for targeted enforcement for those work sites that have been identified as the most dangerous, establishments with injury and illness rates that are above industry average.

We must also want to step up our efforts to end wage discrimination and expand employment opportunities for all men and women. Today, working women earn only 75 cents to the dollar compared to men. Only part of this gap can be explained by differences in workers' education, experience, and occupational characteristics, and the rest appears to reflect persistent discrimination in pay. As part of the President's Equal Pay Initiative, our request for ESA's Office of Federal Contract Compliance Office (OFCCP) includes $4 million to increase outreach, education, and technical assistance to Federal contractors. OFCCP will assist contractors by providing additional tools to assess current pay policies and practices and make any necessary improvements.

We have also targeted abusive and exploitative child labor, both home and abroad, through a comprehensive strategy of enforcement, education and partnership. But we can do more. In the new global economy, we have an opportunity to lift millions of people into a worldwide middle class and a decent standard of living without exploiting children. Promoting international core labor standards and improving worldwide enforcement of laws is vital to this effort. Achieving expanded opportunity and security for American workers has become increasingly dependent upon how effectively the U. S. addresses the international challenges of economic globalization. To support these efforts, we are requesting $35 million to promote core labor standards throughout the world, with $25 million for a major new ILO-

based multilateral program designed to help developing countries implement core labor standards building their own safety nets, and $10 million for technical assistance on these issues in support of U.S. bilateral relationships including training in occupational safety and health, local economic development, dislocated worker services and social insurance reform.

These requests for worker protection will benefit our country by looking after the most precious of our natural resources—the lives of our workers and their families. The requests are essential to the well-being of working men and women in the United States and abroad, and so every worker stands to benefit from these proposals.

JOB CORPS

Question. The General Accounting Office (GAO) reported last November that the Labor Department was overstating the success of the Job Corps program. Specifically, GAO found that only 14 percent of Job Corps enrollees satisfied all their vocational training requirements, even though the Labor Department reported that 48 percent of all enrollees complete their vocational training. GAO also questioned the Labor Department's statistic that 62 percent of the jobs obtained by program participants were related to the training they received; 4 out of 10 of the claimed placements did not relate to the enrollee's vocational training. What is your response to GAO's serious questions regarding the achievement of Job Corps?

Answer. We have closely reviewed GAO's report and their interpretation of Job Corps data and definitions, and have undertaken a series of actions in response. In addition, we had several initiatives under way at the time the GAO report was issued that address issues previously raised by GAO.

Regarding the number of enrollees completing their training requirements, the GAO report questioned Job Corps' use of the term "completer". In concert with employers, Job Corps had developed competency-based instruction in a number of vocational offerings where an overall Training Achievement Record (TAR) includes several levels of completion or "step-off levels". Under this system, TARS identify all the skills necessary to master a certain profession and then separate those skills into skill sets that reflect a graduation between beginning level proficiency and mastery of the relevant vocation. Job Corps establishes a variety of completion levels within each vocation with a goal of establishing a preliminary completion level that will make the student employable at an entry level in the vocation and at a high wage, and an appropriate number of completion levels in between.

As currently defined by Job Corps, the term "completer" refers to a student who has completed at least one skill level within their chosen vocational training. An "advanced completer" refers to a Job Corps student who has completed all the skill sets within their chosen trade. It was the categorization of students who have not completed all the skill sets within their vocation as "completers" that caused GAO to question Job Corps' success.

The definition of completer is important because the recently enacted Workforce Investment Act (WIA) establishes that completers are one of the two categories of student that attain the level of a Job Corps graduate and are therefore rendered eligible for the expanded post graduation services required by the WIA. Job Corps' goal is to ensure that all "completers" have achieved a skill level that makes them employable at a reasonable skill and wage level and is demonstrative of a marked level of achievement in Job Corps. Accordingly, we believe that WIA graduates eligible for enhanced post graduation services should include students who are currently referred to as "advanced completers" as well as those currently defined as "completers". In response to the GAO report and in order to ensure that the established completion levels render graduates employable at a reasonable skill and wage level in each trade, Job Corps has undertaken a comprehensive and detailed analysis of vocational completion. This analysis considers time spent on-center by students, levels of completion achieved, and incentives provided to students to remain in vocational programs in order to attain maximum benefit. In addition, we are developing vocational competency testing to assess student vocational skills and provide feedback in the actual skills attained. We expect to complete this work by July of 1999. Where changes to existing TARs are warranted, we will take the appropriate corrective action. Ensuring that Job Corps' TARs are effectively preparing students for employment and that sufficient incentives exist to encourage students to complete as much of their training curriculum as possible is central to ensuring betters job placement results and long-term earning gains for Job Corps students.

Regarding job training matches (JTMs), we have already initiated changes to improve the accuracy of the data for this important performance indicator. Over the last year we initiated the change from classifying JTMS by the Dictionary of Occu-

pational Titles to the Occupational Information Network (O*NET) System. In making this change, we have restructured our classification codes to ensure that only those students who are trained and matched in the same or a closely related occupation will be considered a job training match. For example, under the old system someone who was trained as a cosmetician but who entered employment as a sales clerk would be considered a match because they are both services occupations. Under O*NET, we have designed classification codes so that there are far fewer job training matches allowable for each vocational training program—someone trained as nurses aide, for example, will only be counted as a job training match if they are placed in a job specifically related to the skills they attained in nurses aide training (i.e. nursing home aide, hospital aide, etc.)

In addition, as part of the implementation of the new O*NET system as the basis for the crosswalk between type of training and placement occupation, we are developing more stringent quality control and oversight procedures to preclude questionable matches. We anticipate that these new controls will be in effect early in Program Year 1999.

We had previously informed the GAO that we would implement the O*NET system by January 1, 1999, and that the new controls would be operational by March of the same year. However, we moved the full implementation date to July 1, 1999 to coordinate the timing with a new program year and the Phase I implementation of WIA. This will allow us to implement O*NET along with the new definition of "graduate" and the requirements for establishing expected levels of performance focused on outcomes of graduates (including placement in training-related jobs) required under WIA.

Question. At a cost per enrollee of $16,771, is Job Corps still a cost-effective program?

Answer. Yes. Job Corps expenditures represent a sound and productive investment in America's youth. Per enrollee costs in Job Corps (estimated in the fiscal year 2000 budget at $16,771) are higher than those in most other federal training programs chiefly because Job Corps is a residential program and the others are not. Job Corps is a full-time, year-around program that provides housing, meals, medical care and a variety of other support services to the significantly disadvantaged young people who become enrolled. While a small percentage of students participate on a nonresidential basis, the residential aspect of Job Corps clearly contributes greatly to the success of its students. Job Corps centers provide a secure environment in which basic education, vocational training and social skills development services can be delivered with maximum impact.

Although the Job Corps expenditure per-student may appear high, the return on the public's investment is more than commensurate in terms of increased student productivity and earning power, reduced welfare expenditures and reductions in societal costs from criminal behavior. A well respected study conducted in the late 1970s and early 1980s by the Mathematica Research Corporation demonstrated that Job Corps returns $1.46 to society for every $1.00 it spends. An updated study is currently underway and we are confident that it will confirm that Job Corps continues to yield a net societal benefit of substantial dimension.

Question. GAO also found that a high proportion of the job placements of Job Corps participants were in low skills jobs. What actions are being taken to change the vocations for which Job Corps is preparing its participants to increase their wages?

Answer. Job Corps, as part of its ongoing effort to improve quality of training, has taken a number of steps to enhance vocational training for its students and the quality of jobs they ultimately obtain.

At a national level, we perform an annual assessment of vocational training programs, including placement outcomes, to enable us to identify programs needing improvement. In addition, Job Corps centers will be establishing Industry Councils composed primarily of employers to analyze local labor market information, review center vocational offerings, and make recommendations to the Department for any training areas which should be modified or changed. This will help centers ensure that the training they provide will enable students to get quality jobs in the communities to which they will be returning.

We have initiated third party independent competency tests for students completing 17 selected vocations. The tests confirm competency attainment of students, and also assist Job Corps identify course content and materials that require improvement. Where changes to existing vocational training programs are warranted, we will take the appropriate corrective action.

At the beginning of PY 1998 $15 million was allocated to Job Corps centers to upgrade vocational equipment and classrooms. In determining how to best utilize these funds, centers are working with employers to develop plans to bring state-of-

the-art equipment to existing courses and to develop new course offerings for training in occupations offering the best potential for long-term employment at a living wage.

New policies have been implemented to give Job Corps centers flexibility to integrate academic and vocational curricula so they will be able to adapt their training to meet the needs of students and employers.

We continue to upgrade the vocational curriculum and associated equipment requirements to meet changing labor market needs with input from employers to ensure that vocational courses meet industry standards.

Job Corps is also integrating school-to-work principles in center programs to enable students to participate in project-based learning to gain critical employability skills.

All of these actions are designed to enable us to make sure the training students receive in Job Corps will enable them to successfully enter long-term employment.

Question. Your budget includes $10 million to study the impact of the Family and Medical Leave Act. Why does it cost so much for a study?

Answer. This research is needed to provide broad based and comprehensive data on family and medical leave, including employer practices, employee usage, and barriers to balancing family and business demands. The data gathered should prove extremely useful to the business community, workers, the public, and policy makers in determining how worker productivity is affected by the availability of leave. Of particular interest is the direct impact on businesses, large and small, as they institute new leave policies, independently or in response to legislation, and the impediments to use of family and medical leave to balance the demands of work and family.

In its 1996 report to the Congress, the bipartisan Commission on Family and Medical Leave Policies recommended eleven areas that needed additional research, including studies of employer "best practices" and the impact of family leave policies (both voluntary and statutory) on (1) child development and family welfare; (2) the economic performance of businesses; (3) temporary, part-time, and contract workers; and (4) containment of health care costs of the nation, businesses, and families; employee morale, productivity, turnover and retraining. We believe the research proposal contained in the fiscal year 2000 budget request is entirely consistent with the recommendations of the bipartisan Commission.

NEW JOB TRAINING PROGRAMS

Question. Madam Secretary, this request is the first budget authorized under the Workforce Investment Act of 1998, which repeals the Job Training Partnership Act as of July 1, 2000. This new law is intended to increase State and local flexibility, streamline services, and consolidate job training programs. Yet your budget proposes creating 6 new categorical job training programs at the national level, which are as follows: Skills Shortages Grants, Rewarding Youth Achievement, Right Track Partnerships, Reemployment Services Grants, Work Incentive Grants, and AgNet. Why are you proposing so many new job training programs instead of strengthening existing programs?

Answer. Much of the consolidation of employment and training programs under the Workforce Investment Act is at the "street level" through the creation of a One-Stop service delivery system. Thus, even though services provided at a One-Stop service center are funded by various One-Stop partner programs administered by various Federal agencies, from the customer's perspective service delivery is "seamless." This means that the customer knows that he or she can access a variety of needed services at the One-Stop—rather than being referred from program to program, or place to place.

In addition to this street level consolidation, the budget consolidates some programs that were formerly separate. For example, the Summer Youth and Youth Training Grants programs under JTPA have been combined into a single youth program under the Workforce Investment Act, and separate State education coordination and older worker set-asides in JTPA have been eliminated.

The initiatives mentioned are intended to respond to problems that are currently not being addressed. For example, Right Track Partnerships, Skill Shortage Grants, and Work Incentive Grants each utilize the newly created Workforce Investment system. The Right Track Partnership initiative will provide $100 million in competitive grants to Empowerment Zones/Enterprise Communities and similar areas to keep low income youth from dropping out of school and to assist recent dropouts in returning to school.

Skills Shortage grants are competitive grants which will be made to a consortia of local workforce boards and national skill alliances to identify skill shortages and

target resources on industries struggling to fill jobs, identify workers needing training, and provide training and job placement services. The Administration is also requesting legislation to finance these Skill Shortage grants with fees paid by employers applying for foreign workers through labor certification programs. Once enacted, these fees will be used to finance Skill Shortage grants, and the $40 million in budget authority being requested in the Dislocated Worker program for these purposes will be eliminated.

The budget also includes $50 million for competitive Work Incentive Grants to partnerships or consortia in each State to improve access, accommodation, benefits, services, and employment opportunities, through One-Stop centers, to individuals with disabilities.

Rewarding Youth Achievement is not a new categorical program, but rather a demonstration within Youth Opportunity Grants providing economically disadvantaged youth in high poverty areas with longer-term summer jobs opportunities and bonuses for academic performance. Similarly, AgNet is not a categorical program, but rather an information system devoted to the agriculture industry which contains job opportunities and worker resumes. Finally, Reemployment Services Grants totaling $53 million will provide increased reemployment services to Unemployment Insurance claimants through the States' existing employment service programs.

SKILLS SHORTAGES INITIATIVE

Question. You are requesting bill language to earmark $40 million for a skills shortages initiative to fund grants to local workforce boards to identify skills shortages and target resources on industries struggling to fill those jobs. Why do you need a bill language earmark? Can you give us an example of the type of project you would contemplate funding?

Answer. The $40 million requested to be earmarked in the bill language, is for national grants for targeted dislocated worker projects under WIA, which is subject to legislatively defined distributions through the formula and the 20 percent set aside for national emergency grants, technical assistance and demonstration projects. However, the skill shortage initiative will have a close connection to the programs under WIA and what will be learned through the initiative will have impact on the programs.

These funds will be used for grants to projects that retain dislocated workers in industries struggling to fill jobs in these shortage areas.

Question. You are also requesting authorizing legislation to pay for this program through user fees. Why should Congress appropriate funds for this program before user fee legislation is enacted?

Answer. The Administration is seeking legislation to collect user fees from employers seeking foreign workers under the permanent alien certification program. Once enacted, these fees, similar to those collected under the recently authorized H1–B program for temporary visas for foreign workers, will be used for the Skill Shortages grants and for federal administrative costs in ESA. At that point, the budget authority requested ($40 million) will be reduced and the initiative will be financed by fees. Providing appropriated funds will allow the planning and start-up of this initiative to proceed in a timely manner, while the legislative process for the user fees is underway.

RULEMAKING PROCESS FOR ERGONOMICS

Question. On February 19, 1999, the Labor Department outlined its new proposal for a standard to protect workers against musculoskeletal disorders, although I understand a formal proposal will not be issued until September, and won't be finalized until sometime in 2000. Why will it take so long to put an ergonomics standard in effect?

Answer. OSHA's draft proposed ergonomics program rule has just completed a sixty day review by a Small Business Regulatory Enforcement Fairness Act (SBREFA) Panel, as required by the amended Regulatory Flexibility Act. OSHA will now need to respond to the comments made by the panel and to prepare a new draft before sending the proposed rule to OMB for review. OMB review normally requires up to 90 days. These two review processes will not be completed until September, at which time OSHA intends to propose the rule in the Federal Register.

Publication in the Federal Register begins the full public participation part of the rulemaking process, during which the public comments on the rule, questions OSHA and other witnesses in public hearings, and submits post-hearing comments to the agency. The public comment process will likely not be complete until sometime in the year 2000. Once the record in the rulemaking is closed, the agency must analyze and provide responses in the preamble to the final rule to all substantive comments

made by the public; revise the final rule to reflect these comments; and submit the rule for OMB review before publication in final form. Although the rulemaking process is slow, it is designed to ensure that all interested parties have time to comment on the rules that Federal agencies promulgate and that agency rulemakers review these comments carefully and base their regulatory decisions on the evidence in the record as a whole.

COSTS AND BENEFITS OF PROPOSED ERGONOMICS RULE

Question. What do you estimate will be the implementation costs to employers, and the long-term savings from reduced injury rates?

Answer. At this time, OSHA has only developed a very preliminary estimate of the first year costs and benefits of the draft proposed ergonomics program rule for use by the SBREFA Panel. According to these rough estimates, the proposed standard would have first year costs to employers of $3.5 billion and would return direct cost savings of $4.7 to $14 billion in MSDs prevented.

REQUIREMENTS OF PROPOSED ERGONOMICS RULE

Question. Briefly describe your ergonomics proposal, and the regulatory burden it will place on employers.

Answer. In a typical year, covered employers whose employees do not incur an MSD (estimated to be 75 percent of all covered employers) would only be required to become familiar with the proposed rule, i.e., to become aware of their obligations if a work-related MSD occurs in their facility. Employers who are engaged in manufacturing and manual handling operations would need to establish a basic program, unless they already have one. The basic program would only require employers to tell their employees about ergonomics hazards, how to identify those aspects of their jobs that pose ergonomic risks, their signs and symptoms, and how to report them to the employer. The employer would also respond to these reports in a timely manner. An estimated 626,000 (1997 BLS data) employers who actually have MSDs in their facilities would need to implement the full ergonomics program, which requires hazard analysis and control, training for affected employees and their supervisors, and medical management. Thus, the draft rule tailors the program any given employer needs to implement to the magnitude of the ergonomic hazards in that employer's workplace.

NATIONAL OCCUPATIONAL INFORMATION COORDINATING COMMITTEE

Question. What will be the impact of your budget proposal to zero out the $9 million appropriation for the National Occupational Information Coordinating Committee (NOICC)?

Answer. The Job Training Partnership Act authorizes NOICC, but it is repealed and replaced by the Workforce Investment Act of 1998, which does not authorize NOICC or its activities. Thus, NOICC and the State Occupational Information Coordinating Committees (SOICCs) will close down by July 1, 2000. However, Section 118, Occupational and Employment Information, of the Carl D. Perkins Vocational and Technical Education Act of 1998 (Perkins 98) authorizes the Secretary of Education to continue many of the activities and services currently carried out by the NOICC and SOICCs. If Section 118 is funded and supported and Education adopts the services and products developed by NOICC and SOICCs, most products and services can be continued and expanded and the impact on customers should be minimal. In addition under the Workforce Investment Act, individuals will have expanded access, through the One-Stop delivery system, to labor market and career information through tools such as ALMIS, America's Talent Bank, and O*NET. The Department and NOICC will ensure an orderly phaseout and close out of the NOICC and SOICCs by June 30, 2000.

STATE SPENDING OF WELFARE-TO-WORK GRANT FUNDS

Question. Total outlays for the Welfare-to-Work program in fiscal year 1998 were $16 million out of the $1.5 billion awarded. And outlays for the program in fiscal 1999, up through February are $64 million. What is your explanation for the low rate of expenditure so far in the Welfare-to-Work program?

Answer. Thirty-nine of the forty-eight states and territories (81 percent) that submitted Welfare-to-Work (WtW) grant proposals received their formula grants in the last two quarters of 1998. States that received grants in the last quarter of 1998, including California, New York, Illinois and Florida had some of the largest welfare caseloads in the nation. We expect the rate of expenditures to accelerate in 1999, as states get their programs up and running, and move further along in smoothing

out start-up issues related to recruitment and referral. Given previous experience with implementing new welfare programs, such as JOBS, a slow start up is not unexpected. The 48 WtW States and territories face the challenge of completely revamping a 60 year-old system.

Question. The Administration estimates that outlays for the program in fiscal year 1999 will total $872 million. How have you arrived at this number when outlays have been moving at such a slow pace?

Answer. The outlay estimates were determined when little information was available on the actual spending by States. Also, the estimates assumed that almost $899 million of the fiscal year 1999 formula funds would be awarded by March, 1999, our original goal for receiving fiscal year 1999 State plans. As of April 19, 1999, only five States have approved plans and there are ten State plans pending approval.

We now know that the time needed to implement this program and enroll individuals in it is taking much longer than anticipated, largely because both the grantees and the administrative structure are new. The States and other entities administering this program are quickly gaining experience, and there is no doubt that we will soon see a fully functioning program, putting former welfare recipients into jobs.

Question. Are States having difficulty spending this money, or is there simply not enough demand?

Answer. The demand for Welfare-to-Work (WtW) funds is tremendous; however, expenditures have been slowed by two issues: (1) strict eligibility requirements that may exclude the truly hardest to serve, and (2) the difficulty in developing participant referral systems.

The strict eligibility criteria requiring that 70 percent of the funds be spent on individuals who are long-term welfare recipients and have two of three specified barriers to employment has limited states' ability to serve many truly needy individuals and has slowed recruitment. For example, an individual who has a reading level below the 8th grade may be ineligible for WtW if that person holds a high school diploma. Under the Department's proposed reauthorized program, this eligibility criteria will be simplified, requiring long-term recipients to meet only one employment barrier and allowing States to serve more of the neediest individuals. Approximately 1 million adults on TANF are estimated to meet the proposed hardest-to-employ eligibility criteria and more than 1 million noncustodial parents are projected to be eligible for WtW services under the proposed reauthorization.

Second, State workforce development systems continue to build relationships with State welfare systems. A February 26 GAO report on welfare and workforce agency coordination indicates that one of the major challenges that remains in reforming welfare is developing working partnerships that bring the workforce development and welfare systems together. The feedback of grantees to the Department of Labor supports this finding: grantees indicate that the difficulty of developing participant referral systems has been a factor in slow start-up. A series of jointly sponsored HHS-DOL conference calls and workshops scheduled to take place in May and June will bring together these two systems to address referral issues.

In addition, in rounds one and two of the WtW competitive grants, over 1,400 applicants across the nation requested more than $5 billion in grant assistance while DOL awarded $468 million to 126 grantees.

Question. Why would we need the additional $1 billion you are requesting for this program in fiscal year 2000?

Answer. A strong economy combined with welfare reform has resulted in a steep decline in the numbers of families receiving welfare. But our job of aiding the neediest is not finished. Those individuals who remain on the rolls encounter more serious barriers in their road to employment, including having poor basic skills, physical or learning disabilities, minimal work experience, limited English proficiency, substance abuse problems and domestic violence problems. As time limits on welfare receipt begin to take effect, these individuals are in particular need of targeted assistance to help them gain, retain and advance in employment. WtW can continue to help individual get or keep a job through wage subsidies, direct job creation or other work support, even after they have exhausted their TANF benefits. For those who have found a job, WtW makes sure they keep that job and make a full transition to self-sufficiency.

WtW is also an important tool in helping noncustodial parents meet their obligations to their children. While TANF has historically focused on custodial parents, states and local communities are using WtW funds to find new ways to help noncustodial parents build their capacity to pay child support. The proposed reauthorization will expand the WtW focus on fathers and strengthen the links to child support enforcement.

Finally, the demand for competitive grants is a useful indicator of the importance of this program at the local level. The Department has received more than 1,400 applications, requesting approximately $5 billion in the first two rounds of competition, in which the Department awarded $468 million to 126 grantees in local communities throughout the nation. More than 250 members of Congress wrote to the Department in support of the competitive applications from their communities. A reauthorized WtW will allow funding for additional competitive grants to local communities.

Question. Couldn't funds available from the Temporary Assistance for Needy Families, which also has large unspent carryover balances, also be used for job training for welfare recipients?

Answer. According to the most recent data on TANF expenditures, states have obligated between 80 and 85 percent of their fiscal year 1998 TANF funds. In fact, close to half the states have obligated all of their fiscal year 1998 funds. In addition, many states have made considered choices to save these funds in the event of state population increases or an economic downturn.

Welfare-to-Work, as opposed to TANF, is targeted to serve the hardest-to-employ welfare recipients. WtW funds are an essential component of helping move the most disadvantaged welfare recipients into sustained employment. As part of the workforce development system, WtW is better positioned to link welfare recipients to the workforce. While the TANF block grant is based on historical spending patterns, most WtW funds flow automatically through the states to the communities with the greatest needs. WtW funds can be used to employ noncustodial parents of children on welfare and other individuals who are not recipients of assistance, whereas many states could not use TANF monies for this purpose without extensive changes to a state's TANF plan. Finally, because they are administered by local workforce boards, WtW funds ensure the involvement of local communities and businesses.

PARENTING EDUCATION

Question. Madam Secretary, I understand that your Department is developing programs for parenting education as part of the welfare-to-work initiatives. I've seen in Alaska the need to help parents on welfare develop skills in parenting, especially as they prepare themselves to enter the workforce, and I support these efforts. I've been talking about the need for parenting education with Janet Reno, Donna Shalala, and Secretary Riley as well. Parents who know what their responsibilities are to their children are probably the most important determinant of all in raising their children with a good chance to lead healthy and productive lives.

Can you tell me what you and the Department are doing about parenting? Would you be willing to work with these other Departments on a consolidated approach to training parents?

Answer. Good parenting skills are important for the success of children, youth and young adults in the worlds of education, work and to become a contributing citizen. Our Out-of-School Youth demonstrations provide what we call "Life Skills Training" which includes training for parents with children and being able to address the need to work and the need to be good parents. The life skills training component of our programs focuses on both "hands-on" demonstrations and assistance, as well as literature and other sources of information that are made available to participants. Assistance includes home visits, information on dietary needs, being a positive role model, maintaining an orderly home environment, getting kids to school, health issues, and social issues. The project in Barrow, Alaska is developing a component to provide training and assistance with parenting skills. This program is currently being expanded to include all the villages of the Northern Slope.

Other training and employment projects to be funded in Anchorage and Nome will include a Life Skills training component. To work on these efforts with Attorney General Janet Reno, Secretary of Health and Human Services Donna Shalala and Secretary of Education Riley could only increase the benefits to the program participants and I look forward to establishing linkages with other agencies to focus on this subject area.

"ALASKA WORKS" PARTNERSHIP

Question. Madam Secretary, there is a shortage of trained and experienced skilled construction workers in Alaska. There are about 13,000 persons employed in the construction industry in Alaska today, and an estimated need for another 1,000 skilled workers in 1999. The Alaska Department of Labor estimates that in 1996, over $91 million in wages were paid to non-residents of Alaska working on Alaska construction jobs. At the same time, our Alaska Native people are under-represented by almost 40 percent in the Alaska construction industry, according to a 1998 report

issued by the University of Alaska, Anchorage. Many of our rural Alaska Native people are chronically unemployed and have not been trained in the skills which would qualify them for these well-paying jobs in Alaska. As part of the "Alaska Works" national program to train minorities and women for skilled jobs in construction and other fields, the "Alaska Works" partnership will be proposing a demonstration project to train chronically unemployed, unskilled Alaska Natives and other residents to qualify for the many skilled well-paid jobs that are expected to be available in Alaska over the next several years. Will your Department work with us to help train Alaskans to work as skilled workers on Alaskan construction projects?

Answer. We look forward to working with Alaska Works to train Native Alaskans for high skill, high paying jobs in Alaska. Currently, our Bureau of Apprenticeship and Training is working with construction firms that work in Alaska developing Apprentice positions for Native Alaskans in the construction trades.

We are aware that Native Alaskans are under represented in the building trades. One of the training components in our Barrow, Alaska project is to train residents in construction. We are also working to get employers to help design the training curriculum and provide on-the-job training opportunities and jobs when individuals complete their training. This is on a very small scale. However, we look forward to increasing the size of this program throughout the villages on the Northern Slope and in other areas of the State.

In Barrow our grantee, the Ilisagvik College, conducts a Building Maintenance program which renovates the college facilities. Recently, the college has added construction training to this program. Students are learning through hands-on experience by constructing a building on the college campus. We intend to continue this effort and expand training opportunities to residents of the villages of the Northern Slope.

CALCULATION OF UNEMPLOYMENT RATES IN ALASKA

Question. For some time I have been puzzled by statistics issued by the Labor Department which purport to show that unemployment rates in many small, remote Alaska villages and towns are only three or four percent, where we know, in fact, that true rates of unemployment are in fact between 50 and 90 percent. We know that, especially in the winter, many villages only have four or five paying jobs, and that many residents would like to work, but no jobs are available. Some months ago, my staff met with representatives of the Department on this issue. My staff was told that in order to be considered "unemployed", a person must be registered with an unemployment office and report back on a regular basis on the results of job searches. Madam Secretary, in most Alaska villages, there are no unemployment offices. Villagers cannot travel back and forth from village to village because there are no roads. These Alaskans want to work and are available to work. But they are not counted as unemployed. Since official unemployment figures are used to determine eligibility for a broad range of federal programs, this method of determining unemployment has extremely negative consequences for many Alaskans who are in great need of our help. Will you work with us to develop an accurate method of measuring true unemployment in rural Alaska and in other parts of the country where the same situation may apply?

Answer. Various programs of the Bureau of Labor Statistics (BLS) provide statistics on the employment status of the nation's population. The Current Population Survey (CPS) is the source of national monthly labor force measures. For state or local areas, the BLS Local Area Unemployment Statistics (LAUS) program uses the CPS data in estimating methodologies that generate monthly statistics at the State and area levels.

All of these BLS programs use the same official concepts of "employed," "unemployed," and "not in the labor force." These concepts are periodically reviewed by independent commissions, and have been used, essentially unchanged, for decades. Of particular significance to areas like Alaska Native Villages is the requirement that individuals who do not have a job must actively seek work in order to meet the classification of "unemployed." If they do not actively seek work perhaps because they believe there are no jobs in the area or because of adverse weather they are considered "not in the labor force." Since the unemployment rate is defined as the percentage of the labor force (employed plus unemployed persons) that is jobless, persons who are not actively seeking work and therefore not in the labor force are not counted in the unemployment rate.

It is important to note that "actively seeking work" is not limited to the filing for or receipt of unemployment benefits. Registration at a local unemployment office is

only one of a number of methods of job search that would classify a person as unemployed.

In Alaska, LAUS estimates are developed for the State and 37 other areas, the smallest of which is Yakutat Borough, with a labor force of just over 300 persons and a preliminary 1998 unemployment rate of 12.4 percent. Although published LAUS subcounty or sub-borough estimates are restricted to areas above 25,000 population, the BLS provided the Research and Analysis Section of the Alaska Department of Labor with decennial census data that could be used to develop Alaska Native village estimates that are consistent with official methodology. The census data were provided to the Alaska agency to assist the State in complying with Welfare Reform legislation that required official LAUS unemployment rates in administering the Temporary Assistance to Needy Families (TANF) program. Subsequent amendments allowed for the use of employment/population ratios in administering TANF at the village level. These employment/population ratios are likely to be more appropriate for the situations of the Alaska villages that you describe.

The BLS believes unemployment is only one of a series of measures of labor market conditions. The economic statistics used to administer federal programs are determined either through law or by program regulation. Perhaps in certain circumstances the unemployment rate is not the appropriate measure to use for a specific decision such as fund allocation or eligibility determination. If so, that Federal agency responsible for administering the specific benefit program may need to look at their criterion.

YEAR 2000 COMPUTER COMPLIANT

Question. The Y2K deadline is fast approaching. Can you assure the public that people receiving unemployment insurance benefits and retirees receiving pension checks will receive them in January 2000?

Answer. In addition to ensuring that all of DOL's mission critical systems were repaired or replaced by March 31, the Department has worked actively with our program partners, such as State and local government agencies and private sector organizations, in preparing for the Year 2000 and ensuring the uninterrupted delivery of benefits and services to America's workers. People receiving UI benefits should anticipate no interruptions in service in January 2000. The Department and our program partners will direct attention to providing retirees with a similar level of confidence in the receipt of their pension checks.

Unemployment insurance

The State Employment Security Agencies (SESAs) successfully passed an early test of the UI program's readiness for the year 2000 in January 1999 when the SESAs' automated systems first encountered the year 2000 in the processing and payment of new claims. UI systems establish a benefit year ending date, 52 weeks from the filing date, for each first-time claim; therefore, claims filed in January 1999 have benefit years extending into the year 2000. Although some SESAs used temporary system "fixes" to process new claims while permanent Year 2000 repairs or replacement systems are completed, claimants' benefits were paid on time.

Both DOL and the SESAs recognize that additional actions are required to fully prepare UI for the transition into the next century. For example, SESAs must ensure that permanent solutions to achieve full Year 2000 compliance for UI benefit, tax and wage record systems are implemented. In accordance with UI guidance, SESAs are required to complete Independent Verification and Validation (IV&V) assessments of their systems to identify and correct any remaining risks of Year 2000 failures. The SESAs are preparing and will test Business Continuity and Contingency Plans which present the agencies' plans for delivering benefits and essential services in the event a Year 2000 problem arises, despite the program's best efforts. The Department will continue to provide oversight, training and technical assistance to our UI program partners, to monitor the progress of the SESAs, and to coordinate actions to notify the public of the UI program's readiness for the Year 2000.

Pensions

The Department is reasonably confident in the readiness of many of the regulated service providers, e.g., the insurance industry, banks and investment firms. Articles in the April 1, 1999 issue of Best's Review support our conclusion that most major insurance companies are prepared to transition into the Year 2000 without significant problems, and the Comptroller General recently voiced his satisfaction with the condition of the banking industry. Periodic reports from the Securities and Exchange Commission and the successful Wall Street test conducted on April 11, 1999 indicate a high level of readiness by the Nation's investment firms. The Department

will be directing its attention during the remaining months to the progress of medium-sized plans serving more than 100 but fewer than 1,000 participants.

The Department has conducted extensive outreach efforts to alert officials who administer 700,000 private sector pension plans and 4.5 million other employee benefit plans of the Year 2000 problem and their responsibility to correct their systems, ensure the Year 2000 compliance of service providers and prepare for contingencies. Outreach efforts have included news releases, information on the DOL website, and meetings with officials at all levels of the employee benefit plan community.

In conjunction with our pension industry oversight and enforcement responsibilities, the Department has undertaken several Year 2000 initiatives, including working with the American Institute of Certified Public Accountants to ensure that its 1998 Audit Risk Alert contained a section giving guidance to employee benefit plan auditors on informing clients about preparedness. In addition, the Department's investigators are reviewing Year 2000 progress as part of their civil investigations of employee benefit plans across the country.

Question. I notice that you are proposing a sizeable increase in spending on Information Technology (IT). To what extent is this an outgrowth of the Y2K focus? How important are IT investments to your ability to get your job done?

Answer. The Information Technology (IT) cross-cut will allow the Department to tackle common problems across agencies in a cohesive and consistent manner. The $30.7 million included in our budget is to ensure that the Department meets the legislative mandates of the Clinger Cohen Act, Paperwork Reduction Act, Computer Security Act, Year 2000 challenge and the Office of Management and Budget's (OMB) policy on the management of information resources and technology within the Department.

The cross-cut includes funding for program specific DOL IT initiatives such as ETA's America's Labor Market Information Initiative, ESA's LMRDA Electronic Reporting and Internet Public Disclosure and FECA IT/Paperless Injury Compensation projects, and PWBA's Form 5500 Information Dissemination Internet Project, all of which improve delivery of our services to our customers. It also includes funding for the IT infrastructure needed to enable us to continue the efficient and effective accomplishment of departmental and agency missions, strategic goals and objectives.

Proactive planning in our IT infrastructure area is allowing the Department to look ahead and plan for transition to a Departmental IT Architecture and improved web services capability. Combined, these two projects will allow the Department to tackle common problems across agencies in a cohesive and consistent manner.

Although Y2K helped the Department to focus its IT resources on solving problems beyond immediate Y2K concerns, it is only one component of the Department's planning and budgeting efforts for fiscal year 2000 and beyond. We also have included funding to begin an important new initiative; compliance with the mandates of Presidential Decision Directive 63, Protecting the Nation's Critical Infrastructure. This Directive focuses additional, much needed attention on security, in acknowledgment of our country's growing dependence on interconnected cyber-systems, and those systems' potential vulnerability to hostile attack. I am committed to ensuring that the appropriate security plans and controls are implemented.

Continued IT spending is critical to the Department's ability to support our missions and provide essential services to the American Public. The Department's new, enhanced IT Capital Investment Management process is being implemented this year and is being used to select, control, and evaluate the Department's IT investments as required by the Clinger Cohen Act. This will continue to ensure that the Department's IT investments are carefully managed and evaluated as to their effectiveness.

ALASKA PROJECTS

Question. I am very pleased with the Alaska projects that have been undertaken with employment and training funds.

Could you describe the status of the project provided with $500,000 in dislocated worker funding for the Bethel Native corporation in Bethel, Alaska to provide high technology computer-based training to Alaska Natives, and what you envision for the future?

Answer. The fiscal year 1999 Appropriations Conference report language directs the Secretary to provide $500,000 to the Bethel Native corporation in Bethel, Alaska. Departmental staff have been in contact with the representatives of the Bethel Native corporation. The Department will fund this grant during Program Year (PY) 1999 (on or after July 1, 1999) upon receipt of a viable proposal from the grantee.

Question. Can you describe the status of the following projects provided with funding and what you envision for the future?

—$1.25 million in pilots and demonstrations funding for Ilisagvik College in Barrow, Alaska;
—$250,000 in pilots and demonstration funding for the Koahnic Broadcasting, Inc. in Anchorage, Alaska;
—$1 million in pilots and demonstrations funding for Kawerak, Inc. in Nome, Alaska, for continuation or initiation of vocational job training programs for Alaska Natives; and
—$1 million in pilot and demonstration funding for the Alaska Federation on Natives Foundation, consistent with the goals of section 13 of the bylaws of that organization, to develop and train highly skilled Alaska Native workers for year-round employment within the petroleum industry.

Answer. Funds for these initiatives will become available July 1, 1999. Staff have already had communication with Ilisagvik College in Barrow, the Koahnic Broadcasting, Inc., in Anchorage and the Kawerak, Inc. in Nome to provide guidance on submission of their proposals which will include a detailed description of the education, training, employment and supportive services that will be provided to participants.

We plan to work with each grantee to develop a system of training and employment activities that will link with U. S. Department of Labor, Employment and Training Administration's formula funded programs, State and local funded programs which will leverage resources and make it possible for the services to continue beyond these special funds. We are also looking forward to developing partnerships with other service providers funded by other Federal Agencies to be able to address needs of participants that cannot be supported with Employment and Training funds, i.e. health care, alcohol and drug treatment and housing.

FAMILY AND MEDICAL LEAVE ACT

Question. In your briefing on the DOL budget you mentioned supporting expanding the FMLA to include smaller businesses. The President has claimed that this will not be a burden on small businesses. On what basis is such a claim made?

Answer. The President has proposed lowering the coverage threshold for FMLA because a great many workers are not covered by the current law. He believes this expansion will not be a burden on smaller firms. The FMLA does a good job of accommodating business interests with the needs of working men and women. The bipartisan Commission on Family and Medical Leave's report to Congress, entitled "Workable Balance," provides some interesting data on the impact of the statute on businesses. That study suggests that employers have not had serious problems complying with the law. Smaller firms tended to have fewer problems than did larger firms. The Commission also found that more than nine in ten covered employers said it was "very easy" or "somewhat easy" to administer. We believe expanding coverage to more small businesses will help workers without harming employers.

Our enforcement experience supports this view. As of September 30, 1998, the Department's Wage and Hour Division completed action on 13,500 complaints—a small number given the millions who have taken time off under FMLA. Nearly ninety percent of the complaints alleging an FMLA violation were successfully resolved—many with a simple phone call.

We have gone to great lengths to inform the business community and the public about the law, and our efforts have paid off. The evidence from the Commission's report and the Department's experience suggests that there have not been widespread problems or abuses under the FMLA.

Question. Have you discussed these proposals with small businesses to elicit their views?

Answer. Cost to businesses was a serious concern when the Family and Medical Leave Act was first passed. But most employers covered by the FMLA have found compliance to be relatively easy and low-cost, as the work of the bipartisan Commission on Family and Medical Leave has shown. Nine out of ten employers found the law "very" or "somewhat" easy to administer, and for 89 to 99 percent of businesses compliance with the law entailed little or no cost. In fact, smaller firms tended to have fewer problems than did larger firms. We believe the assertion that expanding the FMLA will be too costly for covered businesses will prove to be as groundless as it was when the law was first passed.

Question. You have also suggested that the FMLA be expanded an additional 24 hours to include parental involvement leave and routine medical appointments. Why do you believe that such leave should be included?

Answer. The President believes that today's working families need more help in their struggle to find the time they need to meet tremendous responsibilities as parents to their school-age children and often, at the same time, to care for elderly par-

ents. The Administration supports amending the FMLA to allow covered and eligible workers to take up to 24 additional unpaid hours of FMLA leave each year to care for children or parents under circumstances not now covered by the law. For example, these 24 additional hours of FMLA leave could be taken to. (1) participate in children's school activities directly related to their educational advancement, such as parent-teacher conferences; (2) accompany a child to dental or medical appointments, such as check-ups or vaccinations; and (3) accompany an elderly relative to medical appointments or appointments for other professional services (e.g., interviewing at nursing or group homes).

Question. Has the Department discovered evidence that would suggest that there is a need for such expansion?

Answer. As the President has stated, we all share a stake in the strength of our families. Our society can never be stronger than the children we raise or the families in which we raise them. Dramatic changes in the workforce and the effects on the family demand a closer look at this issue. For example, according to the Urban Institute, the vast majority of married couples with children are spending more total time in paid work than they did in the 1970s or 1980s. Husbands worked an average of 2096 hours in 1979 and 2159 in 1994. Wives worked an average of 581 hours in 1979 and 1168 in 1994. Many working adults must also care for elderly relatives. In 1997, one-quarter of workers had provided special assistance to someone 65 years or older within the last year.

Mothers in the 1950s and 1960s often did not return to the labor market until their children were in elementary school. In the 1970s and 1980s, most women waited until their children were in preschool. By 1995, 55 percent of women who had a child within the previous year were in the labor force.

Single parents face special challenges in balancing work and family needs. Between 1970 and 1997, single female headed families increased from 17 percent to 27 percent of all families with children, and single father headed families increased from 1 to 5 percent of all families with children.

By expanding Family Leave to cover children's doctor visits and parent-teacher conferences, and other routine but important family activities, we can enable millions more of our fellow citizens to balance their responsibilities at home and at work.

Question. Wouldn't making compensatory time and more flexible scheduling available to overtime-eligible employees accomplish the same goal of providing employees with more flexibility but without the paperwork burden?

Answer. The purpose of the federal rules on overtime pay are quite different than the purpose of FMLA. The Fair Labor Standards Act (FLSA) of 1938 contains an overtime requirement primarily to discourage overtime work and thereby provide additional jobs. The law presumes that employers (not employees) set and control the number of hours to be worked—at least in the absence of a collective bargaining agreement. Overtime traditionally has not been viewed as an employee benefit, but as a financial incentive to employers to hire additional workers or as compensation for having to work long hours. In addition, any use of compensatory time off in lieu of cash overtime wages would only affect nonexempt, FLSA covered employees whowork overtime, not all employees.

Question. As you know, when the FMLA was passed, Congress intended that it be used for childbirth, adoption and "serious health conditions" such as cancer and other life threatening illnesses. In recent years the DOL has, through opinion letters, concluded that a serious health condition is any illness that lasts three days, requires a doctor's visit and a prescription. How is it that a "serious health condition" can now mean the common cold or a hangnail? How can you justify such an expansion?

Answer. The definition of "serious health condition" has been a source of much debate and controversy from the onset centering primarily on employer's concerns that everyday minor illnesses, like the common cold, the flu or sore throats, for example, should not be covered by the law. In fact, as a result of public notice-and-comment rule making process, those illnesses are listed in the Department's regulations as examples of conditions that, ordinarily would not be covered by the FMLA because they do not typically require the kind of qualifying treatment by a health care provider or last very long. On the other hand, a serious, complicated case of the flu, affecting an older worker or a very young child, may meet all of the tests in the regulations for a qualifying serious health condition a period of incapacity of more than three consecutive calendar days that also involves qualifying "continuing treatment" by a health care provider.

In developing the regulatory definition of a "serious health condition," and in explaining of that definition and resolving complaints, the Department relied faithfully and extensively on the express language of the statute and the detailed legisla-

tive history. The Department's intent is to ensure that the definition accurately reflects Congressional intent and the purposes of the FMLA to grant to eligible employees all the protections of the law in situations where FMLA leave is really needed.

The Committee report on the FMLA lists examples of "serious health conditions," but goes on to specifically state that the list is was not intended to be an all-inclusive list but examples of conditions that shared a "general test that either the underlying health condition or the treatment of it requires that the employee by absent for m work on a recurring basis or for more than a few day for treatment or recovery." The Congressional report notes further that each of the examples also involved either inpatient care "or continuing treatment or supervision by a health care provider . . . ." The Congressional report notes elsewhere that the Act's definition of "serious health condition" is broad and intended to cover various types of physical and mental conditions that affect an employee's health "to the extent that he or she must be absent from work on a recurring basis or for more than a few days for treatment or recovery." (See, e.g., Report form the Committee on Education and Labor (H.R. 1), Report 103–8, Part 1 (February 2, 1993). Pp. 40–41.) Wage and Hour opinion letters on this issue do not ignore statements of Congressional intent, but rather track them closely, as does the Department's regulatory definition of "serious health condition."

Question. You have frequently mentioned that the FMLA is "working well" and that there is little burden on employers. You often sight the FMLA Commission survey results as evidence. Yet, as you know, those surveys were conducted before the FMLA regulations were even finalized and before companies had much experience with compliance. Is the Department planning on conducting additional surveys this year to determine both the cost and administrative impact of complying with the FMLA, particularly before considering expansion?

Answer. It is correct that the bipartisan Commission's findings are based on employer and employee surveys conducted in the early years following the enactment of the FMLA. However, we believe the Commission's findings are reliable. The law became effective on 8/5/93 and the interim regulations were issued 6/4/93, two years before the Commission's survey of employers. Although, the final regulations were issued three months prior to the survey period (3/95), we have no reason to believe that the relatively minor changes in the regulations from interim to final versions would affect the outcome of the study.

As discussed earlier, the fiscal year 2000 budget request includes $10 million for additional research on family and medical leave, addressing many of the recommendations of the Commission for further research. This research is needed to provide broad based and comprehensive data on family and medical leave, including employer practices, employee usage, and barriers to balancing family and business demands.

EQUAL PAY ACT

Question. The measured gender pay gap does not account for relevant economic factors influencing wages, such as experience and tenure, years and type of education, hours of work, and industry and occupation, therefore, it is wrong to attribute the measured gender pay gap solely or even primarily to workplace discrimination. Will using the proposed increased funding for equal pay initiatives, which will include training, technical assistance and outreach, effectively satisfy the differences between actual workplace discrimination versus relevant economic factors so that employers can avoid frivolous fines and lawsuits?

Answer. As we have set forth in our appropriations request, we will use the funding to help women obtain and retain employment in non-traditional jobs by identifying and disseminating model employer practices and assisting contractors in identifying resources for recruiting qualified women employees, including through the new nationwide network of One Stop Career Centers established by last year's Workforce Investment Act. In addition, we will increase outreach, education, and technical assistance to federal contractors to help eliminate discrimination in compensation. Providing employers with the tools to identify and remedy pay differences will benefit both employers and workers and thus will reduce the continuing pay gap between men and women. These tools permit employers to self-analyze through the use of techniques that take into account the relevant factors that impact the pay gap.

Question. Finally why do you feel the Equal Pay Act should be amended to include unlimited punitive and compensatory damages, unlike other wage discrimination cases which have limits?

Answer. As you know, the EEOC, and not DOL, is charged with enforcing the Equal Pay Act. Amending the Equal Pay Act, however, could permit the award to full relief, including compensatory and punitive damages, to victims of pay discrimination. Capping compensatory and punitive damages could limit a court's ability to compensate completely a claimant for her losses. It is true that compensatory and punitive damages available under Title VII are capped, but that cap is the result of a legislative compromise and is limited to Title VII. In fact, uncapped compensatory and punitive damages are available under at least the 1866 Civil Rights Act (42 U.S.C. 1981), Title IX of the Education Amendments, and Section 504 of the Rehabilitation Act.

QUESTIONS REGARDING GPRA COMPLIANCE

Question. What specific steps have you taken as the head of the agency to achieve performance-based management within your agency, as required by the Government Performance and Results Act?

Answer. The Department recently prepared a revised DOL Strategic Plan and its second Annual Performance Plan covering fiscal year 2000. These plans, and the management structure that will guide their implementation focus on performance-based management, offer a framework for managing our programs as an integrated Department, and provide a basis for reporting our program results to our stakeholders, our customers, and the American public. The process of developing these plans and using them as a basis for managing our programs reflect a number of specific steps, that the Secretary has taken to make DOL a performance-based, results-oriented Department.

—Each annual planning and budget cycle begins with a Senior Management Retreat to emphasize that we are doing business a different way—focusing our efforts on outcomes, program integration (where this makes sense), and cross-cutting activities. At these sessions, the DOL Strategic Plan is reviewed, the Secretary's program priorities are conveyed to Departmental leadership, and key program goals projected for the budget year.

—A Departmental Strategic and Performance Planning Work Group (SPPWG), comprised of selected senior staff from each DOL Agency, has been established by the Secretary to develop the Department's Strategic and Annual Performance Plans.

—A Management Review Council, comprised of DOL Agency Heads, has been established by the Secretary to coordinate the implementation of major management issues as a single, unified Department of Labor; oversee the strategic and performance planning and budget formulation processes; and to ensure that the goals we have established in our planning documents are regularly reviewed and actively used to manage DOL programs.

—Considering the results of our fiscal year 2000 planning cycle, we have gained good experience in identifying strategic issues, forecasting trends, and consulting with our customers and stakeholders. During the fiscal year 2001 planning cycle, we expect to build on this experience and make further refinements in our assessment of cross-cutting programs and activities, our range of consultation with stakeholders and customers, and the relationship between the strategic issues we identify and the goals we establish for fiscal year 1999–2004.

—Beginning this fiscal year, the Management Review Council is using the plans to manage our programs and assess progress toward achievement of the goals in the fiscal year 1999 DOL Annual Performance Plan. During the program review process, performance goals are reviewed in terms of their meaningfulness in assessing the key objectives of the program. Those goals which are inadequate by this standard will be replaced. Our aim is to have clear measures of performance that are readily understood by our employees, stakeholders, customers and the American public.

—Finally, we need to maintain a performance dialogue with our stakeholders and customers and convey the results of our programs to them. We have shared our program goals with them through consultation on our plans. At the conclusion of the fiscal year, we will appraise them of our efforts against these plans through Annual Program Performance Reports.

Question. How are your agency's senior executives and other key managers being held accountable for achieving results?

Answer. At regular quarterly performance reviews conducted by the Management Review Council and chaired by the Deputy Secretary, each Agency Head reports on the progress of their programs in terms of the goals set for these programs in the Department's Annual Performance Plan. As part of the review process, written progress reports are provided by the Agency Head to the Departmental staff for re-

view and comment. Both the staff assessment of program results and the Agency Head's presentation provide a basis for the Deputy Secretary to monitor the progress of the Department's programs against established goals and to hold key executives responsible for results.

Question. How is your agency using performance information to manage the agency?

Answer. Beginning this fiscal year, Departmental agencies began using the Annual Performance Plans to manage our programs and assess progress toward achievement of the goals we have established in the prior Annual Performance Plan. At the Departmental level, the Department's Management Council is conducting assessments through regular performance reviews. During these program reviews, performance goals are assessed in terms of their meaningfulness in assessing key program objectives. Those goals which are inadequate will be replaced. Our aim is to have clear measures of performance that are readily understood by our stakeholders, employees, customers and the American public.

BLS, as a component agency, uses performance data to manage its agency and to conduct periodic reviews. We also are working to use as many outcome and impact performance goals as possible.

Question. How did program performance factor into your decisions about the funding you are requesting in fiscal year 2000? Please provide examples.

Answer. Internal guidance to agencies in the budget formulation process required that requests for new budget initiatives be related to Departmental strategic goals and include a discussion of expected outcomes with proposed measures and projected cost.

The following are increases for additional measurable performance in fiscal year 2000.

—For the Bureau of Labor Statistics (BLS), $22 million and 101 FTE are included to improve statistical indicators which are essential to the development of economic policy and the ability of businesses, labor and governments to make well informed decisions. Of this total, $6.3 million and 57 FTE will be used to augment the Employment Cost Index (ECI) sample with an addition of 7,000 establishment units to the ECI Sample. The ECI is the Principal Federal Economic Indicator that provides the nation's most comprehensive measure of changes in employer costs for all compensation (including wages, salaries and employer provided benefits).

To expand the application of quality adjustment and accelerate the introduction of new products for rapidly changing industries in the Producer price index (PPI), extend PPI coverage for the first time in the construction sector of the economy, and to enhance the ongoing expansion of PPI coverage of the service sector, the budget includes $3.9 million and 28 FTE.

—For the Employment and Training Administration (ETA), the Workforce Investment Act (WIA)'s Dislocated Worker Employment and Training Activities will provide special, targeted assistance training and employment services to about 840,000 displaced workers in 2000. The budget proposes $1.6 billion for dislocated workers, an increase of $190 million over 1999. In 2000, about 74 percent of those who receive services will be working three months after leaving the program, earning an average hourly wage that represents 93 percent of the wage in their previous job.

Question. What specific program changes have you made to improve performance and achieve the goals established in your strategic and annual plans?

Answer. Fiscal year 1999 is the first year that DOL and its component Agencies are using GPRA goals as a basis for assessing program performance. Management actions to improve performance will flow from an assessment of performance data that is being reported against these measures during fiscal year 1999, as well as from the results of discrete evaluations that will be conducted in specific programs.

Question. How does your budget structure link resource amounts to performance goals?

Answer. DOL's work is organized around three strategic goals which are outlined in the fiscal year 2000 Performance Plan. These goals bridge the Department's many agencies and programs, linking them to the DOL mission. For each of the three strategic goals there are 11 supporting outcome goals that refine and further focus the strategic goals.

Currently, linkage to the budget is provided in the DOL Annual Performance Plan by cross referencing DOL budget activities to the Department's three strategic goals. Our objective with the fiscal year 2001 budget is to further refine this linkage to align funding with the Department's 11 outcome goals.

For each DOL outcome goal, there are supporting performance goals that set specific and measurable target levels of performance for DOL Agency programs for the

fiscal year. While the current budget structure aligns closely with our performance plan goals in many program areas, some budget program activities may be restructured to achieve the necessary alignment of programs.

In terms of further refinements to the budget which would tie funding to performance goals, the Department is not yet in a position to pursue that linkage. Our current efforts are focused on assuring the Department's Annual Performance Plan has a well defined program structure, supported by performance goals that capture the core purpose of each program or activity. Once this is accomplished, we will then address appropriate budget restructuring where needed.

Question. What, if any, changes to the account and activity structure in your budget justification are needed to improve this linkage?

Answer. We are examining our budget account structure, but are not yet in a position to discuss what changes, if any, will help us provide Congress with a clearer picture of DOL programs and activities that facilitate rational decisions on the allocation of resources and paint a clearer picture of the cost of results. Our new process could reduce the number of accounts and budget activities to provide more flexibility within DOL agencies for utilizing available funds.

Any changes would improve the connection between DOL programs and the resources needed to carry them out, and would allow us to demonstrate the real cost of the results we are delivering for our budget dollars. In these periods of tight budget constraints, the Department believes this to be a key element of the GPRA reporting requirement.

Question. Does your fiscal year 2000 Results Act performance plan include performance measures for which reliable data are not likely to be available in time for your first performance report in March 2000? If so, what steps are you planning to improve the reliability of these measures?

Answer. Given DOL projections for the implementation and refinement of data collection and reporting systems, we expect to report some data which is reliable in the first DOL Annual Program Performance Report as we continue to address and rectify various data shortcomings. A key exception, from a timeliness perspective, is the data reported under the Job Training Partnership Act (JTPA) and the Workforce Investment Act (WIA).

—The JTPA and WIA Program Year (PY) corresponding to fiscal year 1999 is July 1, 1999 to June 30, 2000. (The nine month delay from fiscal year to the start of the JTPA program year permits sufficient time to allocate funds in these programs to the states and local jurisdictions.) While having the resources in place at the beginning of the program year offers start-up advantages, end-of-program-year performance data is not available until it is gathered from the states some six months after the end of the program year and 15 months after the corresponding fiscal year has ended. Thus, for the DOL Annual Performance Report for fiscal year 1999, DOL will not have reliable JTPA and WIA data that reflects PY 1999 performance until December of fiscal year 2000.

—In response to the second part of your question, eighty-five; the issue for DOL is not reliability of data, but the timeliness of reporting that must be improved. Lagtime of performance data for all forward-funded programs will continue to be an obstacle.

Question. How will your future funding requests take into consideration actual performance compared to expected or target performance?

Answer. The Department's budget submission is a product of a new and rigorous process, driven by an unusually high level of interagency cooperation throughout the Department which takes into consideration actual performance compared to expected or target performance. Therefore, the budget includes funding for three management crosscuts that are vital to the successful design, development, and operation of all departmental programs to enhance the Department's efforts in the areas of performance measurement, information technology, and financial management. The Department is undertaking initiatives on behalf of several agencies to enable them to increase their capacity to become results-oriented, performance-based organizations. These funding requests will help several agencies develop better performance measures; expand data capacity to establish baselines and collect data for the measurement of outcomes; and establish procedures for assuring the validity and reliability of data systems to support performance measurement. The Department is very committed to working both internally with the Office of Inspector General and externally with GAO, OMB, and Congress, as well as other agencies, to ensure that we accomplish our intended results. To do so, the Department will conduct program evaluations to periodically assess the effectiveness of Labor's programs and activities.

Question. To what extent do the dollars associated with specific agency performance goals reflect the full costs of all associated activities performed in support of that goal? For example, are overhead costs fully allocated to goals?

Answer. The Department maintains cost information for the 11 outcome goals in the Department's Strategic Plan. The Chief Financial Officer cost accounting applications will extend beyond the outcome goal level to developing fiscal year 2000 cost information in support of the performance goals set forth in the Department's Performance Plan. The Department has modified its automated financial system to reflect the costs of associated activities performed in support of DOL's performance goals by having the capability to capture, aggregate, allocate and report costs. The new cost accounting systems have the capability to allow aggregation of costs across agency lines and to allocate direct and indirect costs to the strategic outcome and performance goal levels established in the DOL Strategic Plan.

Question. How were the agency's performance goals and measures developed? How did the agency balance the need to develop attainable measures with the goal of improving agency performance by setting challenging performance goals? Did the agency assess goals and measures for their potential for unintended perverse effects?

Answer. The Department has utilized a top-down and bottom-up approach in the development of its performance goals and measures. Specifically, Secretary Herman held retreats during the first phase of the planning cycle with her executive staff to review departmental issues and experiences from the prior year and to identify and explain her priorities for the coming year. Following a review of the DOL Strategic Plan, the new priorities were incorporated into the development of new performance goals and measures.

—The Secretary also created a departmental-level GPRA staff to provide guidance on the DOL's strategic planning processes. The Strategic and Performance Planning Work Group (SPPWG), comprised of selected senior staff from each DOL Agency was responsible for reviewing the goals and measures developed by the component agencies and for the development of the Department's strategic and Annual Performance Plans. During the planning process, SPPWG relied heavily on component agency program information to ensure that they designed challenging performance goals and attainable measures. The Strategic Planning and Performance Workgroup also examined the goals and measures established by the various agencies to determine which ones would be included in the Department's plans.

—The Department attempted to assess its goals and measures in the context of meeting emerging challenges. In the development of the Strategic Plan the Department fully assessed key external factors that may affect performance: the dynamic changes affecting the future workforce and workplace, namely the changing economy; changes in legislation and regulations; and partnerships.

—In assessing its goals when conducting field inspections, OSHA changed its methodology from one of enforcement to providing compliance assistance. For example, GAO highlighted this in a staff paper on GAO "Best Practice" Study on Performance Management and Measurement, Job Code 233584, dated April 30, 1999, stating: "OSHA found that the decline in occupational injury and illness rates in the early to mid-1990s was attributable to legislative reforms motivated by increases in workers' compensation payments and a growing awareness of workplace hazards among unions, employers, and the insurance industry. Factors such as employment shifts into low hazard industries and under reporting of injury and illness rates were not contributory. OSHA reform efforts affected the agency's inspection strategy and resulted in a renewed emphasis on outreach, partnering, and working cooperatively with employers to address workplace hazards. The change in approach complemented market influences affecting industry, namely, escalating costs for workers' compensation programs and the dawning realization that corrective action was needed to reduce workplace accidents. The OSHA reforms reinforced and supported industry initiatives and contributed to the decline in occupational injury and illness rates."

Question. Has the agency consulted or coordinated development of its performance plan with any other agency that administers similar programs or provides services to similar customer groups? If so, which agencies/programs were involved? If no, why not? Based on these consultations, what, if any, substantive changes were made to the agency's strategic objectives or performance goals and measures.

Answer. During the planning cycle, briefings for Executive Staff were held to better coordinate plans among Departmental Agencies. DOL has conducted consultations with many customers and stakeholders. The consultation process with other Federal agencies is ongoing. There has been some consultation with other agencies on cross-cutting issues, particularly between the Employment Training Administra-

tion and the Department of Education; between the Occupational Safety and Health Administration and the National Institute for Occupational Safety and Health; and between PWBA and the ERISA Advisory Council and other Federal agencies which share ERISA responsibilities.

DOL's consultation efforts with other agencies, including GAO, OMB, Department of Transportation and Coast Guard, led to several changes, clarifications, and improvements in the text of the Departmental plans.

Question. What part of the agency is responsible for overseeing implementation of the GPRA? If it is not the budget office, how does the responsible component of the agency coordinate its oversight activities with the budget office?

Answer. The Office of the Assistant Secretary for Administration and Management, Office of Budget, which houses the GPRA Staff, has the staff responsibility for overseeing the implementation of GPRA and providing guidance on strategic planning and performance management processes for SPPWG and the Management Review Council.

—The Departmental Office of Inspector General also provides input in the GPRA implementation process by providing the Secretary with information on how best to attain the highest possible program results.

—The Chief Financial Officer provides a partnership role in quarterly performance reviews and annual reports in addition to cost accounting responsibilities. Currently, the CFO is developing ways to provide good cost accounting information for the outcome goals in the Department's Strategic Plan. Further, the Department is also developing cost information in support of the performance goals in the Performance Plan. DOL is developing the capability to consolidate data from a variety of program and financial system sources and link that data as needed to meet GPRA performance reporting requirements.

Question. Labor lacks adequate information to assess whether its programs are operating efficiently and are producing intended results. Labor's fiscal year 2000 performance plan acknowledges some missing data. Also, GAO has reported on data problems regarding the Job Corps program and the Davis Bacon Act. What has Labor done to ensure that data sources (particularly the Standardized Program Information report used by the Job Training Partnership Act program and the Outcome Management System used by Job Corps) are complete, precise, timely, and reliable?

Answer. The Department is taking several aggressive steps to overcome management challenges and to address the areas where improvements are needed. First, to assist us in developing solutions to our data problems, we are currently launching an effort to obtain technical assistance to improve our performance data systems, in addition to other component agency-specific improvement initiatives. This technical expertise will assist selected program staff in developing outcome measures and training modules that can be utilized Department-wide. We will also use this resource to begin to address specific agencies and problem areas that have been identified in previous GAO reports. OSHA has already begun conducting record keeping inspections to verify site specific data gathered through its data initiative in response to a GAO recommendation. The Employment Training Administration has launched a major data initiative using contractor support to review its data reporting systems and to develop specific recommendations for improving accuracy, reliability and timeliness. Our aim is to ensure that our systems produce accurate, reliable program performance data.

To ensure that data sources are reliable, ETA has launched a major data validation project employing an independent research firm, Mathematic Policy Research, Incorporated to study the agency's data reporting systems and to develop specific recommendations to ensure that data collected and reported is accurate, reliable and timely. This ETA Data Validation and Quality Initiative is the first step in the design of a comprehensive ETA Data Validation System. This data validation concept is being embedded in the new reporting systems under development as a result of implementation of the Workforce Investment Act (WIA). The contractor will be reporting its recommendations for designing the Data Validation System in early June, and work on the validation system will start immediately thereafter.

With respect to concerns regarding the accuracy of Job Corps data, Job Corps has made several programmatic and policy changes to address the concerns raised by the GAO. Effective July 1, 1998, Job Corps implemented a placement retention measure in its comprehensive Outcome Measurement System. The data collection for both the placement retention measure and the initial placement verification is being conducted by a neutral third party to ensure data integrity. Data integrity and reliability are high priority issues within Job Corps. The Office of Job Corps is working closely with the Office of Inspector General to address these areas.

Question. What performance goals has Labor developed to measure the timeliness and accuracy of its wage data collections, how will they help assess improvement in wage data collection, and what process and criteria did you use in developing them?

Answer. The long-term performance goals that have been established under GPRA for the Davis-Bacon wage survey/determination program are to:

—Survey each area of the country for all four types of construction (residential, building, highway, and heavy) at least every three years, and the resulting wage determinations validly represent locally prevailing wages/benefits; and,

—Update 90 percent of Davis-Bacon wage determinations within 60 days of receipt of the underlying survey data.

The Department of Labor is currently developing two possible alternatives for accomplishing these goals: (1) the Wage and Hour Division is working closely with the Bureau of Labor Statistics (BLS) to explore the use of new or redesigned BLS survey programs as the underlying basis for Davis-Bacon wage determinations, and (2) Wage and Hour is re-engineering the current survey process through the application of new technology and other process improvements. After a review of a broad range of alternative approaches, the BLS and re-engineering alternatives were selected as the two approaches warranting further development due to their potential for improving the accuracy and timeliness of wage determinations.

These performance goals focus specifically on timeliness and accuracy. Wage determinations based on old data or erroneous data will not validly reflect locally-prevailing wage and fringe benefit rates. A timely wage determination is not acceptable unless it also accurately and appropriately represents locally prevailing wages and benefits.

For example, the use of OES data may not yield sufficient information to issue accurate rates for the different types of construction. OES may provide data for electricians in the construction industry as a whole in an area, but not for electricians in building, residential, heavy and highway construction, respectively. Clearly, a wage determination based upon data for the construction industry as a whole would be less accurate than a wage determination reflecting different types of construction. However, there may be other timeliness and accuracy considerations such as the frequency of data collection and the quality of the data collected that would compensate for using broader occupational data. Similarly, the sample survey format utilized by OES may not produce adequate data to issue wage determinations on a county-by-county basis.

At the present time, sufficient data are not available to conclude that both options are, in fact, feasible—either operationally or from a cost perspective. Once we can ascertain whether both options are feasible, we will undertake to assess the relative merits based on the achievability of our established performance criteria of accuracy and timeliness as well as administrability, continuity and—certainly—cost. However, we must first cross the threshold of establishing that both approaches, or some combination of the two, provide a feasible basis for meeting the needs of the Davis-Bacon wage determination program.

Question. Labor's decentralized agency structure challenges the Department's ability to coordinate its activities. This is particularly true in light of the many offices at the federal, state, and local levels that share responsibility for implementing worker protection laws and workforce development programs. For example, GAO reported in 1998 that lack of effective coordination could result in farm worker children working in violation of federal law. Recent passage of the Workforce Investment Act further emphasizes the need for effective coordination to determine whether the agencies' strategic goals are being met.

In light of the passage of the Workforce Investment Act and Labor's highly decentralized structure, how will the Department ensure that effective coordination will occur among its responsible agencies as well as the various federal, state, and local units involved in implementing workforce development programs?

Answer. A variety of approaches has been used to achieve the coordination that is necessary to effectively implement the Workforce Investment Act (WIA). At the Federal level, coordination within Federal Departments and agencies has been achieved through interagency working groups that address such issues as regulations, performance accountability, unified planning, and promoting maximum program participation in, and customer access to the One-Stop delivery system. OMB and NPR usually are involved in such working groups and often are their conveners. Within the Department of Labor, a variety of interagency teams and task forces have been used to achieve coordination and develop products, such as the Interim Final Rule and the State Planning Guidance. The Employment and Training Administration is required by Section 506 (e) of the WIA to reorganize and align functions to carry out the duties and responsibilities required by the Act. ETA is cur-

rently developing plans for such a reorganization, which should facilitate coordination of programs and activities under WIA.

Similarly, a variety of approaches has been used to coordinate with State and local partners in implementing WIA. First, using authority under the Intergovernmental Personnel Act, State and local staff have been brought in to work on the WIA Implementation Task Force. Second, State and local personnel have served on panels to raise and discuss key issues during regulations development. Third, the Department has held regular meetings with representatives of intergovernmental organizations (such as the National Association of Counties and the National Governors Association) on various aspects of implementation. Fourth, the Department has held training sessions on the Interim Final Rule at various locations around the country, at which there was wide participation among the One-Stop partners, including State and local partners. A final means of communication and coordination with States and localities is through our website.

On the issue of interagency cooperation, DOL has established closer working relationships with the Departments of Education, Housing and Urban Development, and Health and Human Services as part of effective implementation of the Workforce Investment Act. The new legislation drives closer partnership among the federal agencies in designing and implementing the performance management systems, including provisions for incentives and sanctions, customer satisfaction, and continuous improvement. Closer integration among programs will improve performance by enabling more effective alignment of resources on the goal of enhancing outcomes for customers.

Question. What initiatives does Labor currently have underway to protect farm workers and their children in the fields?

Answer. Consistent with Secretary Herman's strategic goal to assure a secure workforce: promote the economic security of workers and families, the Employment Standards Administration's Wage and Hour Division has established a supporting goal to increase compliance in targeted low-wage industries, including agriculture. Wage and Hour is placing a particular emphasis on the safe and legal employment of children in agriculture (and other low-wage industries through its multi-prong strategy of enforcement, education and partnerships.

Wage and Hour is expanding its focus on protecting farm workers and their children through its "Salad Bowl" initiative in which tomato, cucumber, onion, garlic, and lettuce crops are targeted under the multi-prong strategy and national compliance surveys are being conducted to measure current levels of compliance and establish the baseline for improving compliance.

The "hot goods" provision of the Fair Labor Standards Act (which prevents the shipment in interstate commerce of goods produced in violation) is an effective enforcement tool to remedy and deter violations.

Aggressive education and outreach to all of these sectors help ensure that workers know their rights and employers are aware of their obligations. This summer, the Department will be renewing its Fair Harvest/Safe Harvest educational campaign focused particularly to farm workers and their families.

Partnerships with leaders in the industry, States, and other Federal agencies augment Wage and Hour's enforcement and education efforts and leverage limited resources.

To assist in efforts to increasing compliance in agriculture, and especially the safe and legal employment of minors, the President sought and the Congress authorized an additional 36 investigators in fiscal year 1999 for the Wage and Hour Division. These resources are being hired, trained and deployed to areas where needed to enhance our agricultural compliance programs.

OSHA is limited by a rider on its appropriation bill as to which employers it can inspect. Generally OSHA cannot inspect farms which have 10 or fewer employees and have not had an active temporary labor camp activity within the preceding12 months. Family members are not considered employees in these cases. In addition, since February 1997, Wage and Hour has taken over enforcement of 1910.142 (temporary labor camps) and 1928.110 (field sanitation) standards, under Secretary's Order 6–96. Nine of OSHA's 23 States and territories that have OSHA approved plans also t/ransferred authority over to Wage and Hour. OSHA retains jurisdiction over temporary labor camps for egg, poultry, or red meat production workers and for post-harvest processing of other agriculture or horticultural commodities. OSHA also has enforcement authority in agriculture for other 29 CFR 1928 standards and certain 29 CFR 1910 standards which are:

—roll-over protective structures for tractors used in agricultural operations (1928.51);

—guarding of farm field equipment, farmstead equipment, and cotton gins (1928.75);

—storage and handling of anhydrous ammonia (1910.111 (a) and (b));
—logging operations (1910.266);
—slow moving vehicles (1910.145);
—hazard communication (1910.1200);
—cadmium (1910.1027);
—retention of DOT markings, placards and labels (1910.1201);
—Also, where appropriate, OSHA can issue a citation under its General Duty Clause (Section 5(a)(1) of the OSH Act).

For the reasons listed above, Federal OSHA's inspection activity, and that of nine of the 23 State OSHA Programs, is comparatively small because most enforcement has been taken over by the Wage and Hour Division. For fiscal year 1998 in the crops, livestock, and animal specialty industries, Federal OSHA conducted 52 inspections, and the State OSHAs conducted 862 inspections. In the agricultural production crop industry, Federal OSHA conducted 25 inspections, and the State OSHAs conducted 761 inspections.

Question. How does Labor plan to measure the success of its coordination of enforcement resources both within the department (e.g. Occupational Safety and Health Administration [OSHA] and the Wage and Hour Division) and between different levels of government?

Answer. Consistent with the Department's strategic and performance planning processes, the Department will measure the success of its coordination of enforcement resources both within the Department and between various levels of government, by gaining information and feedback on an ongoing basis from various agencies, state partners, non federal programs, among other stakeholders and by program evaluations.

The Department has made significant improvements in communication and coordination among cross-cutting enforcement program activities such as those of the OSHA, and the Mine Safety and Health Administration. These improvements can be attributed to the participatory nature of the stakeholder involvement and the participatory nature of the Department's strategic planning process. We recognize that our agencies must work together in ways which increase the cross-fertilization of ideas, information and strategies in order to meet our overall mission.

Question. What is the current status of OSHA's effort to promulgate a national employer work site safety and health program standard?

Answer. OSHA is continuing it's efforts to develop a Safety and Health Program rule. Because the U.S. Court of Appeals' recent decision on OSHA's Cooperative Compliance Program has potential implications for the form a program rule will take, OSHA has decided to conduct additional research. We expect the additional research to be completed this year and anticipate publishing a proposal in the Federal Register by the end of this calendar year.

INTERNATIONAL CHILD LABOR

Question. Madam Secretary, I applaud your efforts in the ILO to help craft a meaningful and substantive Convention concerning the Worst Forms of Child Labor. For clarification, the ILO is a tripartite organization made up of Governments, employers and workers working together to come up with this new convention. I believe that it is important for the United States to ratify this new Convention and be on record as abhorring the scourge of child labor. Can you enlighten us as to the status of the negotiations between the three parties?

Answer. As the President made clear in his State of the Union address, the United States should play a leading role in helping the international community to eliminate the worst forms of child labor. We very much appreciate your support of that role.

At last year's ILO Conference, I emphasized the President's strong support for an effective new child labor convention. I urged the delegates to negotiate a convention that was clear, concise, and targeted to ending the worst abuses. We will continue to pursue that goal. Delegates to the ILO Conference will meet again on June 1–17, 1999, to finish drafting the new convention. After a convention is adopted by the ILO, it will be up individual member countries to decide whether they will ratify the convention.

Question. Can you tell the Committee for the record the significance of having all three parties in agreement?

Answer. Finding common ground among governments, workers and employers will help produce a new convention that many countries can ratify and that truly will make a difference in protecting children.

CHILD LABOR LAW VIOLATIONS

Question. Madam Secretary in your opinion, in what U.S. industry do the most child labor violations occur?

Answer. Not surprisingly, most violations of the Federal child labor law occur in the retail industry. Nearly 60 percent of 15- to 17-year-olds are employed in retail industry—most in eating and drinking establishments. Correspondingly, its in the retail sector that we most often find child labor violations—nearly two-thirds of our cases finding violations are in retail and involve 70 percent of minors employed in violation. And it is in retail employment that most injuries to young workers occur—again, nearly 70 percent of youth who experience work-related injuries are employed in retail.

Children who work in agricultural occupations (about 6 percent of 15- to 17 year-olds) are however, among the most vulnerable workers. Agricultural employment accounts for the largest percentage (40 percent) of fatalities to young workers 17 and under. In fiscal year 1998, Wage and Hour conducted more than 540 targeted investigations in its "Salad Bowl" initiative and found 69 minors illegally employed in the "salad bowl" crops alone (lettuce, cucumbers, tomatoes, garlic and onions).

Question. Madam Secretary, in fiscal year 1999 we provided additional resources to address violations of U.S. child labor laws particularly in the agricultural sector. How are or will these resources being used? Also can you give the Committee an overview of "Operation Salad Bowl" and the "No Sweat" initiative with an emphasis on violations of child labor laws?

Answer. The additional investigators sought and obtained in fiscal year 1999 have been hired, are being trained and will be deployed so as to allow Wage and Hour to enhance its compliance initiatives, which include a focus on child labor, in garment manufacturing (the "No Sweat" initiative) and agriculture (the "Salad Bowl" initiative). The additional staff, when fully trained and productive, will allow Wage and Hour to double its agricultural enforcement program.

Our "No Sweat" garment initiative is a multi-prong strategy of enforcement, education and partnerships which seeks to involve all segments of the industry contractors, manufacturers, retailers, consumers, worker advocacy groups and unions in efforts to promote and achieve labor law compliance. Enforcement strategies typically include targeted strike forces and the use of the Fair Labor Standards Act's "hot goods" provision. Education strategies, which include compliance monitoring workshops, are designed to educate all those involved in the industry and the public about the nature and extent of the labor standards violations and what can be done to remedy them. Partnerships with leaders in the industry, States and other Federal agencies, like Targeted Industries Partnership Program (TIPP) with the State of California, increases the effectiveness of our enforcement and outreach efforts and leverage valuable resources.

The disregard of labor laws in the garment manufacturing industry is rampant and well documented by the Department's recent compliance surveys. For example, our 1998 survey of the Los Angeles garment industry found that compliance with minimum wage and overtime requirements at only 39 percent. The compliance rate in New York City, the second major garment center in the U.S., is only 37 percent (1997 survey). Sweatshops are still very common, and our "No Sweat" strategy is aimed directly at this serious problem.

Similar circumstances characterize agriculture, though compliance surveys are only now starting to be conducted in this sector. Agriculture is subject to very substantial workforce and employer instability, which makes it even more difficult to drive up compliance. However, we are committed to and continuing to expand our focus on farm workers through our "Salad Bowl" initiative in which tomato, cucumber, onion, garlic, and lettuce crops are targeted. "Operation Salad Bowl" uses the same multi-prong approach of enforcement, education, and partnerships to effect compliance. Child labor compliance is emphasized not just in the "Salad Bowl" initiative but also in other local education and enforcement initiatives directed to agricultural employment.

Our increased emphasis on child labor compliance is broader than in garment manufacturing and agriculture, however. While substantial progress has been made in reducing work-related injuries to young workers the occupational injury rate has declined by half since 1992 too many young workers are injured and killed on-the-job. Each year, more than 210,000 young workers suffer work-related injury and nearly 70 are killed. This is unacceptable. And this is why I have established child labor as a high priority for the Department and why the President is seeking even more support an additional 30 investigators in his pending fiscal year 2000 budget, to further expand our capacity to address substantial compliance challenges, including child labor, in garment manufacturing and agriculture.

FAIR PAY

Question. Madam Secretary, I read in the New York Times this morning that M.I.T has issued a report acknowledging that they have a pay equity problem. They report that, although the number of women on their facility grew, the gap between salaries for male and female professors actually widened.

I know that you have made enforcement of the Equal Pay Act a priority and I commend you for that. But there is more to this issue than just equal pay for the same job. I think part of the problem is that we're not paying women the same as men in when they are in different, but comparable, jobs. Do you have any thoughts about what we can do about this?

Answer. First, we applaud MIT for taking the initiative to examine its own workforce and to address the pay problems that it found. The MIT experience confirms that the pay gap is real, even after controlling for factors that contribute to the gap. Self-audits can play a key role in closing the pay gap, and we at the Department of Labor want to offer any Federal contractor the technical assistance necessary to conduct its own self-audit.

Although the EEOC now enforces the Equal Pay Act, I have made enforcement of Executive Order 11246 and the two statues relevant to the Federal contractor community a priority. These laws allow broader enforcement than is permitted under the Equal Pay Act, but do not directly address the condition you mention in your question, women being paid less than men when they are in different, but comparable jobs. Short of a change in the law, I believe there is much that can be done to narrow the pay gap. For example, we believe, that the activities that would be funded by our appropriation request, such as training, technical assistance, outreach, and encouraging the employer community to recognize and resolve pay disparities, are steps that will help to reduce the continuing pay gap between men and women and to open up jobs to women in non-traditional areas.

DISABLED WORKERS

Question. The Administration, I see, is making efforts to help adults with disabilities find meaningful employment that pays a living wage. Can you tell us, Madam Secretary, what these efforts are and what outcomes you hope to achieve?

Answer. The President's fiscal year 2000 budget includes numerous initiatives that will help adults with disabilities find meaningful employment that pays a living wage. Since the start of his Administration, President Clinton has made an extraordinary commitment to making health care more affordable, accessible, and effective for all Americans. Furthermore, the President has recognized the critical link between health care and employment of adults with disabilities and that many persons with disabilities will choose not to return to work because of fears about losing their health insurance.

Reflecting this commitment, I have headed for the past year the Presidential Task Force on Employment of Adults with Disabilities for the purpose of creating a coordinated and aggressive national policy to increase the employment of adults with disabilities. The focus of the Task Force, comprising senior executive branch officials, is to develop recommendations for revising Federal programs and policies in order to reduce employment barriers for adults with disabilities.

The Task Force's work during its first year has been highly productive. All the recommendations from the Task Force have been adopted by the Administration and, as appropriate, included in the fiscal year 2000 budget. Within my Department the fiscal year 2000 Budget includes $50 million for the new Work Incentives Assistance initiative. This program includes two different grant components—Counseling and Outreach grants and Systems Change grants. The objective of both types of grants will be to ensure that persons with disabilities are provided the services needed to find and retain employment.

Counseling and Outreach grants, accounting for $23 million of the $50 million request, will ensure that persons with disabilities have comprehensive information on existing work incentives programs. The complexities of work incentive programs often present a barrier to persons with disabilities returning to work, because of their concern about being unable to earn enough to offset losses in income and health insurance benefits.

System Change grants, which account for the remaining $27 million, will focus on inducing systems change at the state and local level to improve training, employment, return-to-work, job retention, and career advancement for persons with disabilities. The current approach to supplying needed employment services to persons with disabilities is very fragmented and has rendered many of these programs ineffective for persons with disabilities. The Work Incentives Assistance Program would address these coordination and fragmentation problems by creating partnerships

and consortia that would assist in better integrating and coordinating the provision of employment and support services to individuals with disabilities through the one-stop career center systems being established under the Workforce Investment Act of 1998 (WIA).

Even with the expansion of work incentive counseling and planning and more integrated and effective employment and training services, many persons with disabilities will choose not to return to work because of fears about losing their health insurance. Accordingly, these grant programs are intended to complement other provisions in the proposed Work Incentive Improvement Act, such as the Medicare and Medicaid options, which are aimed at reducing the costs of health insurance incurred by persons with disabilities returning to work.

REDUCING INJURY AND ILLNESS RATES

Question. Madam Secretary, I am pleased to hear that since the passage of OSHA in 1970 the workplace injury rate for full-time workers has fallen by about a third—this is a significant success. Yet workplace injury rates are still high. What progress are we making to reduce these numbers?

Answer. You are correct in saying that we have made a great deal of progress in reducing workplace injuries and illnesses, but that many challenges remain. Even with the decline in rates, there were more than six million workplace injuries and illnesses in our nation in 1997. More than 6,000 workers died from on-the-job injuries and many thousands more die each year as a result of chronic diseases related to occupational exposures. To make further progress in safeguarding our workforce, OSHA has adopted a fourfold approach: (1) OSHA will continue to form partnerships with workers, employers, insurance companies, trade associations and anyone else interested in improving workplace conditions; (2) OSHA will use strong enforcement to pursue employers who ignore the rules and endanger their employees; (3) The agency will improve its standards-setting process by developing smarter standards and using teams for each standards project; (4) OSHA will increase its outreach and educational efforts.

The largest single program increase in our fiscal year 2000 budget request is for compliance assistance, to help businesses, particularly small business employers, identify and remove workplace hazards. Among the tools we use are consultation, expert advisors, and publications. Our request includes funds to place a compliance assistance specialist in each area office.

WELFARE TO WORK

Question. I support your efforts to extend the welfare-to-work program. The key to get people off welfare is to give them the skills they need to get good jobs. That's why I supported passage of the welfare-to-work program in 1997. However, I hear from people that the criteria in the statute, for who may be served, is too restrictive. Are you hearing this? How can we fix the problem?

Answer. In creating WtW, Congress deliberately constructed the eligibility criteria to be narrowly defined so that at least 70 percent of WtW funds would reach the most difficult-to-serve TANF population. In addition to meeting a TANF receipt requirement, the 70 percent category recipients must meet two out of three specified barriers. However, for some of our most needy citizens, the eligibility criteria for the 70 percent category are too restrictive. For example, often individuals who hold high school diplomas do not qualify for services under the 70 percent category, even though they cannot read or write above an 8th grade level. To help address the problem, we have encouraged our grantees not to turn away persons ineligible under the 70 percent category, but to serve them under the less restrictive 30 percent category.

In addition, under the WtW reauthorization sought by the Department, we are suggesting a modification to the eligibility criteria so that a TANF recipient must possess only one of the seven barriers to be served by WtW. The barriers are: (a) lacks a high school diploma or GED; (b) has low basic skills (reads or writes below the 8th grade level); (c) requires substance abuse treatment for employment; (d) is homeless; (e) has a poor work history; (f) has a disability; (g) is a victim of domestic violence. We believe that this change in the reauthorized WtW will result in a more successful program that benefits greater numbers of the neediest Americans.

DEFINITION OF REPEATED VIOLATIONS

Question. OSHA has changed its interpretation of its "repeated violation" rule. The result of the change is that if a company has many different locations, a violation of an OSHA standard at one location is predicate enough to constitute a repeated violation for breach of the same standard at any other location. The Seventh

Circuit Court in Caterpillar, Inc. v. Secretary of Labor (Aug. 25, 1998, No. 97–3488) urged OSHA to clarify its procedures under this rule. In fact, the judge noted in his decision that "it would be nice if OSHA would make clear what it thinks a repeated violation is." Further, in its decision, the Court clearly outlines the conflicting interpre-tations of a repeated violation which have developed through case law, agency enforcement priorities, and OSHA's field operations manual and its progeny.

There are two issues of paramount concern with regard to OSHA's interpretation of repeated violations. The first concern arises out of the confusion which has developed because of the varying interpretations of the term "repeatedly" and whether or not OSHA's apparent interpretation of that term is intended as a "statutory" interpretation or merely as a "setting of enforcement priorities." The second issue of concern is the fact that, as noted by the judge, "the larger the company, the more likely is a violation to be repeated, even if the larger company is just as careful as the smaller one."

It is this second issue that is most troubling. Current OSHA interpretation of repeated violations unfairly discriminates against and penalizes employers who have multiple locations, and the Seventh Circuit Court clearly recognized this in its decision. The Court's decision in Caterpillar, Inc. solicits your assistance in clarifying this issue and removing the ambiguities that presently exist. What prompted OSHA to make such a big shift in policy on repeat violations?

Answer. OSHA has not made a big shift in policy on repeat violations. The Occupational Safety and Health Act itself does not define the term "repeatedly" (which appears in section 17, the section on penalties), but the statute has long been interpreted -with the approval of all the courts that have addressed this issue—as meaning two or more substantially similar violations. As the Occupational Safety and Health Review Commission stated in its 1979 Potlatch decision, neither the fact that "the violations occurred at different worksites" nor "the length of time between the two violations" is relevant to a determination of a violation as repeated. Rather, the Commission noted that such factors might be relevant to the assessment of an appropriate penalty.

OSHA's field guidance manuals have also taken into account the location of, and length of time between, the two violations. In Caterpillar, the Seventh Circuit Court of Appeals raised the question of whether the manual instructions are intended as an interpretation of what a repeated violation is or as "merely an intent to establish enforcement priorities." As previously noted, it is OSHA's interpretation that a repeated violation is simply one that is substantially similar to at least one prior violation by the same employer. The field guidance on time and geographic limitations is solely a matter of enforcement discretion.

The agency, in other words, has chosen not to cite for repeated violations as fully as its interpretation of the term would allow. Thus, under OSHA's current enforcement policy, the agency looks at a company's nationwide history for only the last three years with respect to high gravity serious violations where there is a high probability of death or serious physical harm to an employee. In the agency's view, it is this type of violation that an employer, once cited, should be particularly diligent in eliminating at all of its facilities.

Question. In light of the Court's August 25, 1998 decision, what changes has the agency made to clarify this issue?

Answer. The Seventh Circuit expressed its concern that "substantial similarity" must be defined in a manner that will "distinguish between repeated violations that reflect simply the scale of a company's operations and those that indicate a failure to learn from experience . . . the citation for the first violation [must] place the employer on notice of the need to take steps to prevent the second violation." OSHA is in full agreement with this principle and believes that both its enforcement guidance and the case law of the Review Commission and the courts have been consistent with it. Application of this principle assures fairness even to very large employers. In Caterpillar, for example, the court agreed with OSHA's determination that there was substantial similarity between the company's failure to provide a mechanical barrier guard on a power press to protect the operator's hands and the company's subsequent failure to assure such protection on another press by allowing an electric barrier (electric eye) to be disabled.

HEALTH CARE—DOL'S PATIENTS' RIGHTS REGULATION

Question. The Department of Labor is considering regulations to revise ERISA's benefit claims appeal procedures. DOL's stated intention is to improve the timeliness and fairness of claims procedure regulations. However, businesses—whether large or small—will be unable to comply with the new timetables under the regula-

tions and will instead tend to approve all claims. The raging health care inflation that prevailed through the late 1980's and early 1990's will certainly return.

DOL received more than 700 comments to their proposed regulation, 131 from NAM members alone. Even organized labor (Bob Georgine) has indicated some discomfort over the proposed regulations. To their credit, DOL scheduled three days of public hearings (2/17–19) to receive further public comment. The NAM testified on 2/18 that the DOL should withdraw and re-propose their regulation or, better yet, set up a negotiated rulemaking procedure that will allow regulators and businesses to come to terms on new regulations with which the marketplace can live.

Given the tremendous outpouring of negative comment on DOL's proposed benefit claims regulations, will you consider withdrawing the regulations?

Answer. While we agree that numerous concerns have been expressed regarding various provisions of the Department's patients' rights proposal, we believe that the process that we have been pursuing to update the procedural standards governing benefit determinations under ERISA has been both constructive and informative. This process will, we believe, lead to an appropriate and beneficial regulation. We began the process in September 1997 with an invitation for public comment on whether and to what extent ERISA's claims procedures should be updated and amended. We received over 90 comments in response to that invitation, many of which identified specific areas in need of change.

The need for changes in the claims processing area was further evidenced by the recommendations of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, as well as the changes taking place at the both the Federal and state level in response to a wide variety of problems in the health care delivery area. In addition to reviewing the more than 700 comments and the testimony presented on behalf of over 70 organizations, we are continuing to work with interested persons in an effort to ensure that our decisions with respect to a final regulation are made on a fully informed basis. We remain committed to working with all interested parties to improve patients' rights in this area.

We also should point out that many of the comments we received were very positive and supportive of the principles underlying the proposed regulation. We are reviewing these comments, along with those that expressed concerns, in order to craft the final regulation. We expect that the final regulation will benefit from this process.

Question. Many agencies (including the DOL in at least one case) are utilizing negotiated rulemaking procedures to create a less adversarial approach to rulemaking. Would you consider withdrawing the benefit claims regulations in favor of a negotiated rulemaking procedure?

Answer. We recognize that numerous concerns have been expressed regarding various provisions of the Department's patients' rights proposal. We also have received many favorable and supportive comments. We believe, by carefully reviewing all comments, that the process that we are pursuing to update the procedural standards governing benefit determinations under ERISA will produce an appropriate and beneficial regulation. In addition to reviewing the more than 700 comments and the testimony presented on behalf of over 70 organizations, we are continuing to work with interested persons in an effort to ensure that our decisions with respect to a final regulation are made on a fully informed basis. We are committed to working with all interested parties to improve patients' rights in this area.

Question. The 106th Congress is likely to work on managed care legislation. Given the likelihood of congressional action, would you consider withdrawing or placing these regulations on hold until Congress has had time to fully debate these same issues?

Answer. As representatives of the Administration have testified before both House and Senate committees, we believe that there is a need for strong and enforceable Patients' Bill of Rights legislation. The Administration supports Congress's efforts to enact such legislation and will continue to work actively with the Congress to assist in developing that legislation. We also believe it is appropriate for the Department to continue its consideration of regulatory issues attendant to strengthening patients' rights while Congress works to consider legislative approaches to ensuring American workers and their families are provided the protections they both need and deserve. As we move forward, we welcome the opportunity to discuss our progress with you.

ADMINISTRATIVE COSTS—WORKFORCE INVESTMENT ACT

Question. Under the old Job Training Partnership Act private industry councils were able to charge between 15 percent and 20 percent of their budgets to administrative costs. The new Workforce Investment Act allows these regional boards to

have only 10 percent of their budgets listed as administrative. While I am certainly not advocating excessive administrative costs, many in the State of Wisconsin are concerned that they will have to cut their administrative budgets in half. This is especially troubling in light of the way the Department of Labor defines what an administrative cost is versus a direct cost. For example, the cost of issuing a check to a participant for tuition reimbursement may be considered an administrative cost even though it directly benefits the participant. There is also concern that computer repair costs on training work stations will also be considered administrative.

Wouldn't it make sense for the Department of Labor to allow private industry councils and workforce investment boards to charge expenses that directly benefit participants as direct costs and not as administrative?

Answer. Section 128(b)(4)(C) of the Workforce Investment Act (WIA) required the Department of Labor to develop and issue a regulation to define the term "administrative costs" after consultation with the Governors. The Department expanded the scope of the consultation process to include representation from many of the intergovernmental organizations and a number of other stakeholders. The Act also required that the definition be consistent with generally accepted accounting principles.

In developing the definition of administrative costs, the Department considered the Office of Management and Budget circulars which address cost principles as well as the definition of administration included at Section 6 of the Rehabilitation Act of 1973 as amended by Title IV of the Workforce Investment Act. Additional program specific factors, including the 10 percent local level administrative cost limitation and the operation of the program through one-stop centers, were also considered.

After considerable discussion, it was agreed that "function" would be the basis for determining whether a cost should be classified as administrative or programmatic. The WIA Interim Final Rule, published on April 15, 1999, incorporates this approach. This new way of thinking about administrative costs was presented at the recent WIA Implementation Training sessions. Those participating were given the opportunity to work with the definition through the use of a practical exercise and many thought that the change would make it possible to operate the program within the administrative cost limitation imposed by the Act.

However, the definition has not yet been tested. In order to do so, the Department is arranging for a CPA contractor to review the actual Job Training Partnership Act costs incurred by ten volunteer local areas during the program year July 1, 1997 through June 30, 1998, and reclassify the costs as programmatic or administrative based on the new WIA definition. The results of this test should give us a fuller picture by the end August. In addition, we will consider all comments received on the WIA Interim Final Rules approach to defining administrative costs prior to promulgating a final rule.

JOB CORPS

Question. First, I would like to point out that Wisconsin has the lowest percentage of youth in poverty served by Job Corps than any other State. Only 3 percent of our disadvantaged young people have an opportunity to participate in the Job Corps program. In 1993, Milwaukee narrowly missed an opportunity to receive a Job Corps site, and recently I have been hearing from folks in that community who are interested in trying again. I hope that Congress and the Administration will be able to find the funds for another round of expansion for Job Corps soon, if not this year then maybe next year.

But I know that Job Corps has pressing problems. The Workforce Investment Act (WIA) gives Job Corps may new responsibilities, but the Administration has not given them any new funds. Under the WIA, Job Corps will now be required to provide support services to, and track, students for twelve months after they leave a Job Corps program. I understand that the President's budget includes only half of the funds needed to carry out this new responsibility.

Could you elaborate on why the twelve month follow-up is an important new part of the Job Corps program, and explain why only limited funds were provided?

Answer. The President's Budget includes an increase of $12.6 million to completely finance the enhanced post graduation support services and tracking required by the WIA. The requested amount will cover the costs of post graduation services and tracking for all graduates—providing the extended, enhanced assistance to Job Corps graduates envisioned by WIA as well as informing us about the employment patterns of Job Corps students for twelve months after graduation. The requested level is based on an analysis of PY 1998 unit costs for various types of placement services and tracking activities and an estimate of the number of students who will

seek repeated placement services in the twelve months following graduation. Without prior experience providing post graduation services for a twelve month period, we extrapolated from our experience providing support services for six months after graduation and estimated the number of students who would require additional services in the second half of the year after graduation. It is our expectation that, consistent with the requirements of the WIA, the requested level will provide these essential services to all Job Corps graduates and will lead to substantial improvements in the overall effectiveness of the Job Corps program.

SENIOR COMMUNITY SERVICE EMPLOYMENT PROGRAM

Question. The Senior Community Service Employment Program serves a crucial need in our communities. Under the new Workforce Investment Act this will be the only program geared toward older workers. It has a proven track record of success. With the workforce so tight in many places around the country, I believe we need to help everyone who wants to enter, or re-enter the workforce. Unfortunately, even though the numbers of older Americans are increasing, the funding for this program has remained constant for three years.

Why has this program not been more of a priority for the Administration?

Answer. We think the Senior Community Service Employment Program (SCSEP) is an important program. In March, the Departments of Labor and HHS transmitted amendments to the Older Americans Act which would reauthorize and strengthen Title V, which authorizes the SCSEP. Overall budget constraints prevent us from proposing increased funding for this important program. We are encouraging program operators to link with activities supported under the Workforce Investment Act. Close coordination between the SCSEP and WIA activities can increase both the quality of services and quantity of participants.

H–2A SHEEPHERDER PROGRAM

Question. I am concerned about the Department of Labor's ongoing review of the Special Sheepherder Guidelines, which govern the employment of legal alien sheepherders through the H–2A program.

A number of sheep ranchers in Idaho and throughout the West utilize H–2A to fill job opportunities for which there are not sufficient qualified domestic sheepherders. The sheepherders who participate in this program perform highly specialized work and make up a critically-needed, stable work force. The program operates under the authority of the Immigration and Nationality Act, the Department's temporary agricultural labor certification regulations at 20 CFR 655, and the Special Sheepherder Guidelines issued by the Employment and Training Administration.

The alien sheepherder program has been in existence for decades. Although the sheepherders are admitted with H–2A visas, this program operates fundamentally differently from the traditional, agricultural H–2A program. In particular, sheepherder job opportunities are not required to be temporary or seasonal, and alien sheepherder may, pending annual recertification, be admitted and employed for more than one year.

I understand DOL will issue revised Guidelines in the very near future, which may include a one-year contract limitation, as opposed to the current three-year contract period. I believe such a revision would have a serious, adverse impact on sheep ranchers and workers.

At the very least, such changes would increase turnover and transportation costs. In addition, they would make employment much more difficult for the workers. There does not appear to be any compelling reason for changing what has been a longstanding practice, one which has been known to and consistently accepted by the Department for many years.

I would like to discuss this important issue with you before any revised Sheepherder Guidelines are finalized and issued. I believe that by working together, we can resolve this issue in a manner that will not have an adverse impact on the program of the sheep ranchers or workers who use it.

Answer. We will be happy to discuss the revised guidelines with you and your staff prior to the guidelines being finalized and issued. The one-year limitation, however, is not part of any proposed revisions. The one-year limitation has been in place for several years, and is spelled out in Part I, Item B–5 of the "Special Procedures" section of the Department's Field Memorandum No. 74–89, dated May 31, 1989, which established the current special procedures for the certification of sheepherders under the H–2A program. Labor certifications for sheepherders have always been issued by the Department for a period of 364 days or less. There have been no instances of certifications of 365 days or more.

Question. One of the requirements set by the Department of Labor for the employment of H–2A sheepherders is for the payment of at least a "prevailing wage", based upon the wage paid to similarly-employed U.S. workers.

In its letter dated March 2, 1999, and received by employers several days later, DOL gave retroactive notice of its determination that the prevailing wage for sheepherders for the 1998–1999 season has increased by 15.4 percent in Idaho and 28.6 percent in California, effective March 1, 1999.

Prevailing wage determinations for sheepherders have been notoriously inaccurate in the past. Several times, determinations have been challenged successfully and amended significantly.

In this case, DOL's retroactive application of a much bigger prevailing wage, without any advance notice puts employers in an unfair position. Either they would have to change radically the compensation they provide, even if the requirement to do so is rescinded later; or else they risk violating the law hoping for a favorable outcome to their challenge to the new determinations. Either way, employment decisions and workforce morale are needlessly disrupted.

I am asking you to consider delaying the effective date of these new prevailing wage determinations until DOL can fully review, and if necessary, conduct another survey and make any appropriate changes. I know employers in Idaho and California have made this same request to DOL and are ready to assist in a timely review and any new survey.

Answer. On March 26, 1999, the Department rescinded the original March 2, 1999 memorandum which established the retroactive prevailing wage rates. The existing prevailing wage rates from 1998–1999 will remain in place until the Department issues the 1999–2000 sheepherder prevailing wage rates in accordance with the procedures established in Field Memorandum No. 74–89. New sheepherder prevailing wage surveys are currently being conducted for Arizona, Colorado, Idaho, Montana, Nevada, and Washington. California has revisited its survey data and has since submitted a revised wage finding. We anticipate publication of the rates this summer, after consultation with interested parties.

CONCLUSION OF HEARINGS

Senator SPECTER. Thank you very much, that concludes the hearing. The subcommittee will stand in recess subject to the call of the Chair.

[Whereupon, at 11:31 a.m., Tuesday, March 23, the hearings were concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2000

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

NONDEPARTMENTAL WITNESSES

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENT OF LABOR

PREPARED STATEMENT OF PATRICIA KNAUB, DEAN, COLLEGE OF HUMAN ENVIRONMENTAL SCIENCES, OKLAHOMA STATE UNIVERSITY

Mr. Chairman and Members of the Subcommittee: My name is Patricia Knaub. I am Dean of the College of Human Environmental Sciences at Oklahoma State University. This testimony is in behalf of the Board on Human Sciences of the National Association of State Universities and Land Grant Colleges (NASULGC). The Board on Human Sciences (BOHS) represents those State Universities and Land Grant Colleges which conduct research, outreach/extension education, and academic programs on workforce development, human development, family and community viability, nutrition and health, food safety and product development. Outputs of our work support industry, professions, and the general public. Our work is supported by federal, state, and private funded grants as well as CSREES formula funds and USDA competitive grants.

The BOHS strongly supports the Department of Labor funding initiatives outlined in the fiscal year 2000 budget proposal. Our member universities are prepared to carry out work in support of those initiatives, especially Workforce Preparedness and aspects of the Secure Workforce.

ENHANCE OPPORTUNITIES FOR AMERICA'S WORKFORCE

The structure of the American landscape has changed dramatically during the 20th century from small and moderate sized family farms clustered about vibrant communities and a valued quality of family life to extremes of large corporate farms and fewer small family operations. Population has shifted to cities and suburbs and small towns have declined or disappeared, often leaving elderly with limited resources and services and displaced farm workers without job skills and economic opportunities. Urban populations have swelled with immigrants, many with limited language and employment skills.

PROMOTE THE ECONOMIC SECURITY OF WORKERS AND FAMILIES

In rural America the decline of the family farm has displaced workers from jobs in production agriculture, from the merchandising and service industries no longer needed to support the agricultural production sector, and left an aging population often without financial support for their retirement. Welfare to Work legislation has heightened the need for new jobs and job skills, quality child care for working fami-

lies, and skills to manage limited resources be it time or money. These needs prevail in urban as well as rural sectors of the country.

Safety nets and transitional skills are needed by those caught in the throes of change, but longer term solutions are needed, such as new viable job opportunities, risk management skills, financial planning and resource management education.

HUMAN SCIENCES RESEARCHERS AND EDUCATORS RESPOND

Human Sciences faculty and outreach/extension educators in all 50 states are conducting programs which directly address the needs of individuals and families stressed by changes in the American landscape and job skill requirements. But they also are educating pK-l2 and college students for greater success in their lifetimes. Further, by virtue of the fact that all Human Sciences faculties are linked through the Board on Human Sciences, interstate programs are carried out, evaluated, and information freely exchanged across the country.

Welfare to Work.—BOHS faculties across the United States are monitoring impacts of the legislation and providing data to state and federal policymakers, designing and conducting programs for welfare recipients on employment skills, nutrition and family resource management, child development and interpersonal relations. Extension personnel provide training to welfare recipients over sustained periods of time sufficient to effect changed behavior and thus assure a higher sustained success rate when recipients transition to the workforce.

Preparing Youth for the Workforce.—High school students are being taught financial management, consumer literacy, job skills and job readiness skills to increase potential success in the workforce.

Retirement Planning.—Human Sciences faculty in several states are conducting education in retirement planning and intergenerational property transfer as well as financial management for handling current needs.

Workforce Transition.—A major need is being addressed by Human Sciences faculties by providing coursework, degree programs, or skill upgrade opportunities to help place-bound wage earners transition from low paying jobs or those which no longer exist. These opportunities are increasingly made available by distance learning technologies so that learners can remain at home or study at times available around work schedules. Service jobs which can be performed from a home computer, development of value-added industries from agricultural or other raw products, or the acquisition of academic degrees in healthcare professions or dietetics are examples of new opportunities being made available to displaced workers.

We applaud the well targeted budget initiatives of the Department of Labor in the fiscal year 2000 budget. Researchers and outreach/extension educators represented by the Board on Human Sciences contribute significantly to the programs addressed in this budget as outlined above. We urge your support of this budget. Thank you for your attention to our commentary. We wish to continue to work with you and the Department of Labor in serving the American workforce.

PREPARED STATEMENT OF THE INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES

OVERVIEW

The Interstate Conference of Employment Security Agencies (ICESA) is the national organization of state officials responsible for workforce security and workforce development services. They administer the nation's employment service, unemployment insurance laws, labor market information programs and, in almost all states, job training or workforce development programs. In most states, these officials are also responsible for coordinating workforce development one-stop centers, and they play an important role in welfare-to-work services. Our members are the lead officials in implementing the Workforce Investment Act which Congress passed last August.

As you know, appropriations for administration of unemployment insurance programs, employment services, labor market statistics, and certain veterans employment programs come from the Unemployment Trust Fund (UTF). The UTF, like the Social Security Trust Fund, is made up of dedicated revenues from state and federal employer-paid payroll taxes. While the trust fund revenues are sufficient to fully fund the operation of these programs, the focus on elimination of the federal budget deficit and the inclusion of unemployment trust funds in budget deficit calculations have undermined the funding arrangements set up by the system's founders. A survey by ICESA in 1997 showed that 43 states were using over $200 million in state funds to supplement federal appropriations for employment security administration.

We just completed an update of this survey and it shows that in 1999, 49 states will be supplementing appropriations for employment security administration with over $400 million in state funds.

Frustration with the federal budget and appropriations process has convinced states that a fundamental change in the administrative funding arrangements of the employment security system is needed. For example, a coalition of states and business interests has developed a proposal to shift responsibility for collection of federal unemployment taxes to the states which would retain most of the funds. More than half of the states currently support this proposal, and the chair of the House Ways and Means Committee, Subcommittee on Human Resources, is expected to introduce legislation this session to address inequities in the system.

ONE-STOP EMPLOYMENT SERVICES

Last year Congress passed bi-partisan legislation—the Workforce Investment Act—that consolidates job training programs and develops an integrated workforce development/one-stop service system. On behalf of the states, we would like to take this opportunity to thank Congress and the Administration for passing this much needed reform. While this legislation was enacted only eight months ago, state and local workforce officials have been moving towards a one-stop service delivery system for a number of years, i.e., ensuring that customers—jobseekers and employers—can access the full array of employment, unemployment, training, and labor market information services easily and through a no-wrong-door approach.

The Department of Labor and virtually all of the states view the state employment services as the essential "glue" that holds together the one-stop systems. The employment service plays a critical role in one-stop service delivery as the primary job finding source for jobseekers and the primary applicant finding source for employers. From July 1, 1997 through June 30, 1998, nearly 18 million people registered with the state employment services and nearly 12 million of those received services from the system beyond registration. Moreover, the highly successful America's Job Bank and related America's Career Kit tools are all built on the states' public employment service system. In any given day, there are over 850,000 job openings on America's Job Bank, making it by far the largest job bank on the Internet. The one-stop grants that have been awarded to every state now have been used to build linked information systems; in some cases these funds have helped integrate services in shared physical facilities, and in others, the funds have been used to develop and implement new customer-friendly technologies and service delivery approaches.

But a successful workforce investment system is more than just computers and nationally-built technologies and tools. The Administration has requested $149 million for these tools and other related initiatives and no increase in funding for frontline service delivery. We ask you instead to commit additional funds to ES state allotments-the foundation of the one-stop center systems and the assurance of universal services for both jobseekers and employers. In addition to their importance to the continued operation and success of state one-stop systems, the state employment services represent the main linkage between employment and training programs and the unemployment insurance system. The employment services are the vehicle to provide job search assistance to unemployed individuals and to ensure their earliest possible return to work.

An $811 million investment in the state employment services is critical to the one-stop systems in the states, to providing effective job search assistance to unemployed workers and saving trust fund dollars, to meeting employers' requirements for skilled workers, and to maintaining and enhancing new electronic tools to efficiently and effectively match jobseekers to available jobs.

UNIVERSAL REEMPLOYMENT INITIATIVE

The states support the long-term goals outlined in the Administration's Universal Reemployment Initiative which include: (1) access to reemployment services for all dislocated workers; (2) reemployment assistance to all unemployment insurance claimants and jobseekers; and (3) access to one-stop centers for all Americans. We support the Administration's request for $53 million for reemployment services grants to provide increased services to UI claimants and an additional $190 million for dislocated workers. By reducing the duration of benefits, reemployment services save substantially more in unemployment benefits than they cost. However, as called for under the Workforce Investment Act, we ask that the members of this subcommittee help ensure the states have flexibility in determining how these additional funds can best be used in their labor markets to accomplish the above-noted goals.

NATIONAL ACTIVITIES—EMPLOYMENT SERVICE

In addition to $811 million for state employment services allotments and the $53 million for reemployment services for UI claimants, there are three programs/initiatives funded under ES national activities that are critical:

The Electronic Labor Exchange.—As stated earlier, the state employment services are the source of the job vacancies currently listed in the highly acclaimed and often cited America's Job Bank. The success of this electronic labor exchange tool is well known. To illustrate its growing popularity, in July 1996, 7.2 million customer transactions were recorded on AJB. In March 1999, more than 2 million transactions were recorded every day. That figure includes more than 350,000 job searches of the 850,000 jobs on the site that come from nearly 80,000 employers. As indicated earlier, this makes America's Job Bank by far the largest job bank on the Internet, and certainly one of the most active. We urge you to continue supporting these exciting tools of the state employment services.

Alien Labor Certification.—Federal alien labor certification laws ensure that admission of foreign workers on a permanent or temporary basis does not affect adversely the job opportunities, wages and working conditions of U.S. workers. State employment security agencies oversee and evaluate the recruitment efforts of employers for U.S. workers and assure that "prevailing wages" are being offered for particular positions before a certification can be issued that the employers can hire foreign workers.

Federal funding for administration of the Alien Labor Certification program by the states has been cut dramatically in recent years—over 50 percent in the last three years—while workload has soared. The combination of this severe cut in funding and a significant increase in cases brought about by changes to federal immigration laws has resulted in huge backlogs—cases pending for more than a year in some states. The frustration of parties to the pending cases has resulted in threats of violence to state agencies. Several states have considered whether to refuse to continue to operate the program under these untenable conditions.

This year, the Administration's fiscal year 2000 budget proposes to transfer the Alien Labor Certification programs and resources from the Employment and Training Administration (ETA) to the Employment Standards Administration (ESA), and to take over most of the states' responsibilities for the program. We look forward to working with the Administration to explore this proposal. In the meantime, we ask that adequate funds—$50.5 million—be provided to the states to address the significant backlogs in this program.

The Work Opportunity Tax Credit (WOTC) and Welfare-to-Work (W2W) Tax Credit are federal tax credits administered by state employment security agencies that encourage employers to hire certain jobseekers. The WOTC and the WtW tax credits were recently extended through June 30, 1999. The Administration's fiscal year 2000 budget request proposes to extend these two programs through June 30, 2000, and proposes a user fee on employers for the certification of these workers. States have worked hard to market these two programs to employers, despite their on-again, off-again availability. Some states are concerned that charging a fee for these programs will result in discouraging employers from hiring these individuals with multiple barriers. As the public policy debate continues on whether or not it is appropriate to charge a fee for this service, in order for state agencies to make timely certifications of eligibility so businesses can claim the tax credit, administrative funds are essential. ICESA requests $20 million for state administration of these two programs.

UNEMPLOYMENT INSURANCE

We would like to thank the subcommittee for the $40 million in fiscal year 1999 appropriations to bring the computer systems of state employment security agencies into compliance with year 2000 requirements. ICESA's members have worked diligently on revising countless lines of computer program code to ensure that payment of unemployment benefits is not disrupted because of the "millennium bug." This investment has paid dividends already; major year 2000 problems beginning in January 1999 were avoided as new claimants became eligible for benefits that can be paid during a benefit year that extends into 2000. Although more work remains, the year 2000 compliance achieved so far would have been impossible for many states without these appropriated funds.

Even during this time when the unemployment rate is low, the unemployment insurance system plays a larger role than one might imagine. In a dynamic economy, workers might lose their jobs in one sector of the economy, but might find new jobs in another sector. During the time they look for new jobs, unemployment insurance provides a safety net of temporary and partial wage replacement. In fiscal year

2000, state unemployment insurance programs are expected to pay $25.7 billion in benefits to 8.3 million unemployed workers and collect $23.5 billion in state unemployment taxes.

The federal-state partnership in the unemployment insurance program has worked well during most of the 63-year history of the program, but recently it has been strained. This strain has stemmed largely from the compelling desire of the federal government to reduce chronic budget deficits and balance the budget by restraining federal spending. Although the federal budget now is running a surplus, there still is a growing gap at the state level between the federal funding needed to administer the program in a proper and efficient manner and the amounts actually appropriated by the federal government. States have tried to make up the difference with their own funds totaling about $70 million, but administration of unemployment insurance is supposed to be funded fully by the federal government from the dedicated trust fund. Even with this $70 million in state money, funding still falls about $100 million short of what the U.S. Department of Labor (USDOL) estimates the program needs for proper and efficient administration

For fiscal year 2000, we urge you to provide $2.626 billion for state unemployment insurance administration—the sum of the President's request of $2.460 billion for state unemployment insurance activities and the federal shortfall estimated by USDOL at $0.166 billion. ICESA members understand the severe spending caps to which the budget process subjects such discretionary spending, but we hope Congress will agree now is the time to correct this imbalance. The proper and efficient administration of employer payroll taxes to finance the UI system and to pay UI benefits to unemployed workers depends on it.

As part the $2.626 billion we urge your support for:

—*$71 million for new unemployment insurance integrity activities*.—These funds are needed to support intensified tax collection, audit and claims monitoring activities. They will be used to: reduce accounts receivable; register and subject to unemployment taxes all new employers immediately; improve collection of delinquent taxes; implement and improve fraud cross match programs; train staff in claims adjudication; and improve detection and collection of benefit overpayments. This $71 million appropriation will be more than offset in the federal budget by increased taxes collected and overpayments prevented or recovered.

—*$7 million for new research efforts*.—Such research efforts include documenting and disseminating promising practices, assessing policy and program alternatives, and evaluating administrative efficiency through the use of new technologies, such as the internet and voice response systems.

Finally, there is one Administration proposal that we cannot support—$40 million of employer-paid unemployment taxes to "expand wage record formats to include an individual's full name in order that records submitted to the National Directory of New Hires can be verified by the Social Security Administration." This proposal might be worthy to assist the child support enforcement program in finding missing parents who owe child support, but it has little to do with the proper and efficient administration of the unemployment insurance system. We suggest that if this is a worthy proposal, the funds should derive from general revenues, and not at the expense of the day-to-day core administrative activities of the unemployment insurance program. Instead, we recommend that this $40 million be used to offset some of the $166 million shortfall described above for state unemployment administration.

LABOR MARKET INFORMATION

Congress's passage of the Workforce Investment Act delineates for the first time in statute a system of labor market information or employment statistics to serve customers. The new legislation makes clear that accurate and timely information is an essential part of our economic infrastructure, providing localized information about employment, jobs, and workers. Such information is an invaluable resource for jobseekers, businesses, educators, and young persons who are planning careers—answering their questions of: Where are the jobs of the future? What changes are occurring in the skill requirements for today's and tomorrow's jobs? Which industries are growing rapidly? Where are layoffs occurring?

State employment statistics directors, consulting with the Bureau of Labor Statistics and other federal agencies, are working to develop the strategic plan for this new employment statistics system of coordinated national, state, and local information. This cooperatively developed system will need to identify and implement the strategies to meet the information needs of customers, eliminate information gaps and advance customers' access to information. The largest challenge will be serving the expanding customer-base called for by the legislation to provide information for

local program delivery and individual customer decision-making. ICESA is requesting adequate funding for this expanding need for localized information called for in WIA. Based upon the 1999 survey discussed earlier, states are already supplementing this critical need for customized local information with over $9.5 million in state supplemental appropriations.

Today's information technology presents a dazzling array of opportunities to integrate and create powerful new tools to meet these needs. Another strength is the experience of the Bureau of Labor Statistics and the states in providing high quality information. Merging these two assets, with funding to meet the new customers' information demands, will provide information to speed the efficiency of the labor market, shortening the time workers are looking for work and employers are seeking workers. ICESA supports $197.5 million for the cooperative statistical programs with the Bureau of Labor Statistics, $37 million for "core products and services," and continuation of funding ($10.1 million) for the research and development activities under the consortia grants to states included within the ALMIS/One-Stop system funding.

VETERANS' EMPLOYMENT AND TRAINING

Congress has made it clear that providing employment services for veterans is a national responsibility. Title 38 of the U.S. Code includes provisions for special employment services for veterans, with priority given to disabled and Vietnam era veterans, through the Disabled Veterans Outreach Program (DVOP) and Local Veterans Employment Representative (LVER) program, which are administered by the state employment security agencies. DVOPs and LVERs serve our veterans population by helping to ensure a smooth transition of separating military personnel into the civilian workforce.

Title 38 also provides formulas to determine DVOP and LVER staffing levels. Since 1990, appropriations for DVOPs and LVERs have not supported the number of positions authorized by the statutory formulas. In fiscal year 1997, the appropriation funded 440 fewer DVOP specialists and 260 fewer LVER staff than authorized by the statutory formulas. Many one-stop centers do not have veterans' staff. ICESA encourages the subcommittee to explore funding above last year's level that would allow at least one DVOP and LVER in every full-service office. Specialized veterans' employment representatives working in one-stop career centers nationwide will help ensure that our nation does not abandon the fine men and women separating from the military.

ADULT, DISLOCATED WORKER AND YOUTH TRAINING

While economic growth in the United States is the envy of the rest of the world, one of the problems of our current economy is a lack of qualified workers for many job openings. The economic sectors where there are labor shortages include entry level jobs, where potential workers need basic skills, as well as information technology jobs where workers with highly specialized skills are needed.

Federal job training programs for disadvantaged adults and youth help to prepare welfare recipients, students, and others to enter the labor force; programs for dislocated workers help these workers develop new skills to participate in the "new economy."

As states and locals move to implement the Workforce Investment Act, adequate funding is critical if we are to be successful. We urge your continued support for the Administration's request of $955 million for adult training, $1.596 billion for dislocated workers, and $1.251 billion for youth job training programs as authorized under WIA.

CONCLUSION

In summary, our message is one of encouraging efficient and effective investment of public resources in a strong workforce security and workforce development system built on the infrastructure that exists today. We are concerned about the continued deterioration in funding for the nation's employment security system and ask that adequate funds be appropriated to support the core, universal programs and services. With your help and targeted investment, we have the ability to link unemployment, employment, labor market information, and training programs together to create a workforce investment system that provides seamless, high quality customer service to America's employers and jobseekers.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NIH/HEALTH

PREPARED STATEMENT OF DR. RAYMOND E. BYE, JR., INTERIM VICE PRESIDENT FOR RESEARCH, FLORIDA STATE UNIVERSITY

Mr. Chairman, thank you and the Members of the Subcommittee for this opportunity to present testimony. I would like to take a moment to acquaint you with Florida State University. Located in the state capitol of Tallahassee, we have been a university since 1950; prior to that, we had a long and proud history as a seminary, a college, and a women's college. While widely known for our athletics teams, we have a rapidly emerging reputation as one of the Nation's top public universities. Having been designated as a Carnegie Research I University several years ago, Florida State University currently exceeds $110 million per year in research expenditures. With no agricultural or medical school, few institutions can boast of that kind of success. We are strong in both the sciences and the arts. We have high quality students; we rank in the top 25 among U. S. colleges and universities in attracting National Merit Scholars. Our scientists and engineers do excellent research, and they work closely with industry to commercialize those results. Florida State ranks fourth this year among all U.S. universities in royalties collected from its patents and licenses, and first among individual public universities. In short, Florida State University is an exciting and rapidly changing institution.

I would like to raise an important issue with you and the Members of this Subcommittee as you make your important allocation decisions in the next several days and weeks. There is growing concern within the scientific and engineering community that the issue of balancing federal R&D is tilting more heavily toward certain areas of scientific research. It is clear that some caution is appropriate as you face those difficult choices, but I would suggest a somewhat different viewpoint. First, it is obvious that the appropriations process is such that R&D funding is spread among several major subcommittees rather than concentrated in one subcommittee. If the latter were the case, that subcommittee and its chair would have the nontrivial task of making difficult allocation decisions among the many and varied R&D agencies. That is not the case and allocations to R&D are heavily dependent on subcommittee allocations from the full Committee in the 302.b process. If your Subcommittee has been successful in that internal allocation process, then it is likely a partial result of the political popularity of some of the programs within your Subcommittee's jurisdiction. The biomedical community has been very successful in making the case for greatly expanded funding for the National Institutes for Health.(NIH). Pressures for increased funding for some other scientific or engineering areas may not have the same appeal as does funding for NIH.

That appears to have been the case previously. It may well be the case again. So in order to recognize and possibly respond to statements about the importance of all scientific areas as the foundation for advances in the biomedical fields from such prominent scientists as Drs. Harold Varmus and Neal Lane, your Subcommittee might consider another way to assist in the advancing of other crucial fields of science while supporting key areas of research and technology development for NIH. In January 1999, the Office of Science and Technology Policy (OSTP) released a report that focused on an analysis of national requirements for synchrotrons, instruments most often funded by the U.S. Department of Energy (DOE). That report, while noting that the number of synchrotrons available were probably adequate, that additional funding was needed to upgrade and improve some of the existing ones. The report encouraged NIH, because of the medical and biomedical applications that can emerge from work done on these instruments, to provide funding for these upgrades. NIH responded and provided substantial funding in fiscal year 1999. The report went on to indicate that at least one additional area might be a candidate for such an NIH effort; that area was nuclear magnetic resonance (NMR) instrumentation.

The need for new state-of-the-art nuclear magnetic resonance instrumentation has been identified and discussed by several hundred scientists who met in Washington, DC last January 1998. The result of that two-day session was a report entitled National Magnetic Resonance Collaboratorium: A Report by the Committee for High Field NMR (August 1998). That report proposed a national collaboratorium of universities and national laboratories which would be linked by internet capabilities. Each institution involved would bring some of the finest intellectual talent available to undertake research on a variety of areas including biology, biomedical sciences, and materials among others. Each institutions would also have major and substan-

tial NMR instrumentation already in place; those instruments would be augmented by new NMR instruments that would be developed at the highest possible fields.

As I mentioned, there are a number of scientific fields and cutting-edge research issues that will lead to incredible opportunities intellectually and economically. From gene research to new materials, from gene regulation to challenges in neurosciences, the higher fields that can be reached in nuclear magnetic resonance will produce some of the most exciting science of the 21st century.

Discussions on the new opportunities have been discussed with key officials at NSF, DOE, NIH, and OSTP. There is excitement at all of these agencies about the prospects and possibilities if high field NMR could be funded. Yet agencies like NSF, which feel the opportunities for such research and development are tremendous, has limited budget growth and opportunity to undertake a major new research instrumentation program even though NSF has the experience and programs to manage such an effort. (The Report on High Field NMR estimated that the cost of instrumentation for 10 sites in the Collaboratorium was estimated at $260 million and annual operating costs approximately $22.5 million.) NIH was also excited about the possibilities, but NIH does not have high field NMR instrument development in their fiscal year 2000 budget. NIH's current instrumentation program, housed largely in the National Center for Research Resources (NCRR), also is not geared to such a large extramural instrumentation program.

This leads me to a suggestion for your Subcommittee to consider, Mr. Chairman. Can NIH resources, as in the case of synchrotrons noted earlier, be devoted to high field nuclear magnetic resonance, as recommended by the OSTP report mentioned earlier, and utilize the management talents and scientific requirements acknowledged by both NSF and NIH to fund such an effort?

If such an effort were to be even considered, my colleagues at Florida State University's National High Magnetic Field Laboratory (NHMFL) and numerous scientists at a large number of key universities and laboratories around the Nation stand ready to discuss these possibilities with you.

Thank you for the opportunity to present these views to you and your Subcommittee.

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The four nursing associations that comprise The Tri-Council for Nursing appreciate the opportunity to present this statement on Title VIII of the Public Health Service Act (Nurse Education Act or NEA), that provides for Nursing Workforce Development and the National Institute of Nursing Research. Ensuring a sufficient number of qualified nurses is a critical issue in providing essential health care in this nation.

The Tri-Council for Nursing collectively represents nurses in every sector of the nursing profession. Its four major national nursing organizations include:

The American Association of Colleges of Nursing representing 534 baccalaureate and graduate nursing education programs in senior colleges and universities across the United States;

The American Nurses Association with 174,000 registered nurse members in 53 constituent state and territorial associations;

The American Organization of Nurse Executives representing 5,000 nurses in executive practice in all types of healthcare settings; and

The National League for Nursing on behalf of 1,674 education agency members representing all levels of nursing education, 37 constituent state leagues representing 40 states, 104 healthcare institutions, 67 academic nursing centers and non-academic agencies, and 6,842 individual members, including nursing school faculty, nurses at all levels of practice, and consumers.

The Tri-Council for Nursing believes that the fiscal year 1999 figure of $67 million for the Nurse Education Act begins to underscore the importance of nursing education programs to the public health. For fiscal year 2000, The Tri-Council for Nursing recommends an increase in NEA funding of 10 percent over fiscal year 1999 funding. This increase would fund the Nurse Education Act programs at approximately $74 million.

The Tri-Council for Nursing expresses its appreciation for the fiscal year 1999 levels of funding for the programs critical to nursing education and research such as the Nurse Education Act and National Institute of Nursing Research at NIH. The 1999 level of funding will be spent to improve the public health, but even this level of funding is insufficient to meet today's demand for nurses.

THE NURSE EDUCATION ACT

The Nurse Education Act was re-authorized in 1998. It is the key source of federal financial support for nursing education programs and nursing students. The NEA and its student loan program primarily seek to encourage preparation of undergraduate nursing students and advance practice nurses (APNs) that are in high demand for care of under-served populations. APNs include nurse practitioners, nurse midwives, clinical nurse specialists and nurse anesthetists.

Nursing workforce issues are of paramount concern now and for the future. The shortfall of registered nurses predicted by the year 2010 is already being evidenced today. (Findings from the National Sample Survey of Registered Nurses, Division of Nursing, DHHS, March 1996) A recent survey of Nurse Staffing concluded that there is a critical shortage of nurses prepared in specialty areas of practice, in all types of settings and in all geographic locations in the country. (Survey on Nursing Staff Shortages: The American Organization of Nurse Executives, 1999)

Information about pending nursing shortages underscores the fact that nurses are integral to effective health care delivery in this country. Having sufficient numbers of qualified nurses to provide patient care is essential to accessible, quality patient care. Nurses provide essential care in every type of care setting: primary care, acute and long term care and care of the chronically ill, disabled and elderly and those at the end of life in a variety of traditional and non-traditional settings. Title VIII provides the essential support needed to ensure the nursing workforce needed to serve the public's requirements for health.

Early warning signs portend a nursing shortage that is very different from previous shortages. This shortage will be challenged by demographics in the nursing profession. The average age of nurses has increased to a high today of 44 years, and will continue to increase. In addition, the demand for nurses prepared for specialty nursing practice will only increase, with the burgeoning patient care technology and continued change in health care delivery. Also, enrollments in baccalaureate nursing programs have declined for the past four years. This year, even Masters program enrollments are down. ("1998–1999 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing," AACN, 1999). These changes compound what could be a serious nurse shortage in the areas typically hard hit by shortages, such as underserved populations and special patient populations.

The NEA provides support for nurse practitioners, nurse midwives, nurse anesthetists and other advanced nursing programs. Nursing administration is now included in recognition of the priority for talented nursing management in health care organizations. Federal funding for these programs has had a significant impact on increasing the supply of nurse practitioners, nurse midwives and clinical nurse specialists. Yet the supply of these well-trained professionals continues to lag behind demand. One of the biggest challenges facing health care organizations today is finding sufficient numbers of qualified nurses for specialty practice.

The NEA provides modest stipends to master's and doctoral students and offers disadvantaged students the help they need to attain nursing education. This essential student support enables individuals who might not otherwise complete advanced education to make major contributions to health care in their local communities and regions.

Emerging unmet health care needs will increase the burden on the already overextended nursing workforce. Areas of emerging serious concern include child health, immune compromised individuals, older persons, low-income individuals, people with mental illness and with substance abuse problems. People in these specialized populations have complex care demands. Their needs are intertwined with social and behavioral issues that are not easily resolved. There is need for innovation to develop care delivery approaches to better meet their special requirements. Interventions are needed now, because there is evidence of ever-increasing demand for care by these groups.

In today's health care delivery, nursing is not only being asked to expand its functions, but also to innovate in care delivery. The scarce resources for care are being experienced in every sector of health care. Nursing, at the core of the health care system, is experiencing the profound effects of reduced resources. In response, nurses are taking on increased responsibility for patient care to meet the challenges of this dynamic health care environment. As the complexity of care continues to increase, nurses and others must continue to stretch their capacity and the resources.

The NEA will continue to encourage programs that link training to the delivery of primary care for underserved people. The Tri-Council for Nursing supports funding for programs that provide repayment for academic loans for nurses who agree to practice in areas of nurse shortage. These areas include public hospitals, community health centers, American Indian facilities and public health services. Having

adequate numbers of nurses caring for patients in these underserved areas is critical to the nation's goals for health.

Through the support of NEA funding, nurses have achieved innovations that have extended the capacity to provide care for people in special population groups. Care provided by nurses in more non-traditional type care settings such as community based health care centers and primary care sites have made care more accessible to the public. NEA funding that has supported these efforts includes both the programs to educate APNs and future nurse faculty.

Nursing is one of the key health professions, working with others to provide care, a point that will be further clarified by the next National Sample Survey of Registered Nurses, scheduled for March 2000. This survey is expected to provide essential information on integrated practice, which is critical in today's environment. We are encouraged by joint efforts by the Council of Graduate Medical Education and the National Advisory Council on Nurse Education and Practice, the Bureau of Health Professions in this regard.

Another area of particular importance is the technologic advances that engender innovation in providing both patient care and education for nurses. The ever-evolving patient care technology allows access to nursing care by patients in a different delivery modes. Many patients obtain their first line care information from telehealth provided by nurses. This nursing care improves both access to care and improves use of health care resources. Technology also allows sharing of professional expertise across settings, thereby closing the gap between care settings in geographically distant locations. Additionally, the technology increases the opportunity for patient and family self-care, which requires corresponding patient education, consultation and support. The new NEA could support projects that allow nurses to design, manage and facilitate these new types of patient care and to best utilize the available resources.

The NEA provides for increasing the diversity of the nursing workforce. Although the number of nurses from minority backgrounds increased at a somewhat faster rate between 1992 and 1998, they only comprise ten percent of the nation's registered nurse population. Funding for this important focus is critical to achieving the goal of increasing the number of nurses who are representative of the populations they serve. The NEA also helps disadvantaged students become nurses.

The new NEA also provides for strengthening the capacity for basic nursing education and practice. The leverage provided through federal influence helps focus critical areas for study and development, essential now that the nation faces the possibility of a critical shortage of nurses. Bold steps must be taken to meet workforce demands in the face of rapid change in demand for care and in the nursing workforce.

The importance of information for present and future planning is recognized in the NEA. The Tri-Council for Nursing strongly supports Division of Nursing initiatives to assess the practice choices made by nurses who have benefited from NEA funding. The estimates on the projected supply and distribution of nurses and work on improved forecasting models could impact readiness for patient care in significant ways.

Informatics is a key aspect of future practice and is important to the Tri-Council for Nursing. Work on the National Nursing Informatics Agenda is of continuing value in addressing interdisciplinary patient care planning and interventions. Future care will be not only interdisciplinary but also across settings in new and different ways.

THE NATIONAL INSTITUTE OF NURSING RESEARCH

The purpose of the National Institute of Nursing Research at the National Institutes of Health is to support clinical and basic research and to answer complex and difficult questions in patient care delivery. NINR funds projects that deal with care of individuals across the life span. The scope of NINR issues encompasses promotion of healthy lifestyles, care during illness, reducing risks for disease and disability and to provide care for the at-risk and undeserved populations.

Research programs supported by the NINR address a number of critical public health and patient care issues and questions. NINR research has added significantly to the science of patient care and has contributed to improved public health and has helped to lower the cost of care, through new ways to meet patient demand for health care. NINR studies have addressed diabetes in Hispanic populations and cardiovascular disease in African American children and youth. A hospital discharge planning and care study using advanced practice nurses has improved health outcomes and decreased readmission rates for low birth weight babies and elderly patients at risk. This year the nursing community is seeking a $20.9 million funding

increase for the NINR for fiscal year 2000. This increase would provide more adequate funding for the scope of NINR programs at $90.7 million.

NINR has supported research, important to key issues in health care today. Among the topics of this research are health and risk behaviors, pain management which is a key aspect for patients and families in end-of-life care, care of patients with immune and infectious diseases, care of patients with cancer, with renal and urinary diseases; trauma care; wound healing and mental health. Studies in the area of healthcare delivery include acute care hospital nursing practices, accountability for patient care outcomes, long term care practices, women's health, neurofunction and cognition and musculoskeletal diseases, metabolic and diabetes and long term care.

The Tri-Council for Nursing appreciates the opportunity to present its fiscal 2000 recommendations for nursing education and research. We look forward to working with the subcommittee to achieve these funding levels.

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American Nurses Association, 600 Maryland Avenue, SW—Suite 100W Washington, DC 20024 202/651–7000 FAX: 202/651–7001

American Organization of Nurse Executives, One North Franklin Chicago, IL 60606 312/422–2800 FAX: 312/422–4503

National League for Nursing, 61 Broadway, 33rd Floor New York, NY 10006 212/363–5555 FAX: 212/812–0393

PREPARED STATEMENT OF WILLIAM G. THILLY, PRESIDENT, AMERICAN ASSOCIATION OF UNIVERSITY ENVIRONMENTAL HEALTH SCIENCE CENTERS

First, let me thank the Sub-Committee for the opportunity to testify and staff members for their helpfulness.

My remarks are intended to provide the rationale for doubling the National Institutes of Health's (NIH) budget by fiscal year 2003 and for a prudent increase in the National Institute of Environmental Health Sciences' (NIEHS) funding above the fiscal year 1999 mark of $368,456,000. We think the amount that would sustain growth and support important new initiatives is at least a 15 percent increase to $423,724,000 for fiscal year 2000.

Much too often public health decisions are made with inadequate and uncertain information. None of us want to be exposed to things that can hurt us or our children. But how do we know what is harmful? Regulatory agencies have to rely on "consensus" opinions of scientists who are forced to make "best guesses" about potential human harm. These "guesses" rely principally on experiments in single cells or animals. One institute at NIH, the National Institute of Environmental Health Sciences has taken on the special responsibility to engage leading researchers to find out what is really happening in people.

The mission of the NIEHS is to reduce the burden of human illness and dysfunction from environmental causes. The NIEHS first focuses on discovering whether a human disease has important environmental risk factors. When an environmental risk is established, then investment is made in discovering the underlying mechanisms and explicitly defining the inherited and environmental risk factors. Their history of defining the role of lead in causing learning deficits in children is probably their most noted accomplishment. But today NIEHS grantees are in pursuit of the environmental factors which have led to a steady increase in Americans' risk of leukemia, lymphoma and brain cancer. Several of the NIEHS Centers are looking at the changes in pollutants city children have been breathing in order to track down the dramatic increase in asthma in the past thirty years. These and other diseases can be documented as increasing from public health records the analysis of which leads to prima facie evidence of the diseases with important environmental causes.

The NIEHS university research is supported through traditional Research Project grants (R01s) and Program Projects (P01s), which are in the "Regular Research Project Grant" (RPG) category. Center Core Grants (P30) and the Superfund Hazardous Substance Basic Research Grants (P42) create interdisciplinary teams necessary for taking on these complex public health problems.

The NIEHS Center for Environmental Health Sciences (CEHS) at MIT illustrates this integration: CEHS has organized all Massachusetts mortality records since 1969 on a town by town basis and have noted that the age dependent death rates for many cancers are highest in urban areas, intermediate in suburbs and even lower in rural areas. Their geneticists have devised means to measure genetic changes directly in human organs and their analytical toxicologists developed the

means to identify chemicals reacting with DNA. Finally, the MIT environmental engineers are defining the pathways of human exposure of these chemicals through air, food and water.

The support for health research by this subcommittee has greatly strengthened our country in biomedical research. Unfortunately, the investment in discovering real environmental health threats through NIEHS or other NIH programs research has not grown commensurate with the NIH budget. Again, we request that you make a timely investment in NIEHS sponsored and other NIH environmental health research this year. We ask for your continued support to double the NIH budget by fiscal year 2003 and for a prudent increase in NIEHS' funding above the fiscal year 1999 mark of $368,456,000. We think the amount that would sustain growth and support important new initiatives would be at least a 15 percent increase to $423,724,000 for fiscal year 2000.

PREPARED STATEMENT OF THE EPILEPSY FOUNDATION

The Epilepsy Foundation is the national voluntary organization that works for people affected by seizures through research, education, advocacy and service. Founded in 1968, its national office is based in Landover, Maryland. More than 60 affiliates across the country provide direct services to individuals and families, including: community education; employment assistance; recreation; professional education conferences; assisted living, and case management and counseling.

Epilepsy and seizures affect 2.3 million Americans of all ages, at an estimated annual cost of $12.5 billion in direct and indirect costs. Approximately 181,000 new cases of seizure and epilepsy occur each year; 10 percent of Americans will experience seizures in their lifetimes; 3 percent will develop epilepsy by age 75.

In 1995, 300,000 children aged 14 and under had epilepsy; 1.4 million adults under age 64 and 550,000 aged 65 and over had epilepsy. Advances in medical treatment enable many people to live normal lives free from seizures. However, epilepsy is a chronic condition that usually requires a lifetime of continual medical treatment and education. Currently, there is no cure for epilepsy.

Many people with epilepsy are able to control their seizures with medications. Approximately 60 percent achieve remission after the first year; 15 percent achieve control at a later date. Yet, in 25 percent of people with epilepsy, seizures resist control and become intractable. For this group, comprising hundreds of thousands of people, epilepsy is a formidable barrier to normal life, affecting educational attainment, employment, and personal fulfillment. Marriage and fertility rates are reduced in both sexes and women face special issues throughout their lives. Children and adults are at risk of brain damage and increased mortality when seizures resist control. The stigma that comes from seizures and societal misconceptions about them remain as facts of life for many with epilepsy.

Epilepsy is a major, unsolved health problem affecting the lives of millions of Americans and their families. The economic impact of epilepsy in the United States is also tremendous. According to the results of a cost-of-illness study issued in 1978 by the Commission for the Control of Epilepsy and its Consequences, Department of Health, Education and Welfare, the national economic burden of epilepsy in 1975, was estimated to be $3.6 billion in direct and indirect costs. Preliminary findings of an Epilepsy Foundation-sponsored study on the 1995 costs of epilepsy (using data from actual cases as a basis for the estimates) show that the total cost to the nation for 2.3 million people with epilepsy and seizures is approximately $12.5 billion. Of this, $1.7 billion (14 percent) are direct medical costs while $10.8 billion (86 percent) are indirect costs.

Indirect costs are primarily employment related. Costs include lost wages from people who have withdrawn from the labor market, reduction in earnings for those still employed, and home production losses based on reduced hours in home production activities. The professional literature and testimony of people with epilepsy who contact the Epilepsy Foundation also support the fact that epilepsy can have devastating effects on employability.

ADVANCES IN EPILEPSY RESEARCH

Epilepsy in children

The severe epilepsy syndromes of childhood produce developmental delay and brain damage that can result in a lifetime of dependence on others and continually accruing costs to the health care system and society. Fundamental research questions about epilepsy in children must be addressed. For example, epilepsy is the most common of all neurological disorders among children, affecting approximately 300,000 infants less than a year old, with 37,000 new cases occurring each year.

What factors in the developing brain predispose children to seizures? How can we predict which children will outgrow epilepsy and in which children will epilepsy worsen? Research has led to the discovery of good predictors for remission or relapse of epilepsy in children. Research focused on the prevention and treatment of epilepsy at this vulnerable time of life should be a national priority.

Women with epilepsy

More than one million women in the United States have epilepsy. Women with epilepsy face epilepsy-related problems throughout their reproductive lives. New research shows that in many women the risk of seizure occurrence varies according to hormonal status and that the mechanisms involved in epilepsy may reduce fertility as well as affect endocrine and other functions.

Research must address the relationship between women's seizures and the hormonal cycle. Despite the need for further answers to this problematic relationship, the role of hormones in epilepsy has received little systematic investigation. Research on epilepsy and women can lead to a cure or amelioration of symptoms.

EPILEPSY IN THE ELDERLY POPULATION

As the population in the United States ages, the number of elderly people with incapacitating seizures, and their costs to society, is also increasing. Currently, it is estimated that 61,000 new cases of epilepsy occur each year among elderly Americans. Stroke, cardiovascular disease, brain tumors and Alzheimer's disease are all causes of epilepsy among people over age 65. However, the cause of epilepsy in the majority of cases remains unknown. Understanding the mechanisms and factors that affect the development of seizures in the elderly will lead to preventing epilepsy in this age group and to other discoveries regarding treatment and cure.

Antiepileptic drug development

One area of great clinical importance to people with epilepsy has been the development of new antiepileptic drugs. Soon, more than a dozen new products and treatment options will be available. The Foundation recommends research support from the NINDS for comparative trials of antiepileptic drugs to allow the clinician to make rational choices for their patients and to assure that their patients with seizures receive the greatest possible benefit from these newly available medications.

Epilepsy surgery

For many persons with epilepsy, surgery has successfully reduced or eliminated their seizures. New technology allows the surgeon to "map" the seizure focus as well as healthy brain tissue. This allows the surgeon to remove the abnormal region (the area of the brain where the seizure originates) while sparing critically functional brain regions. Technologies of laser surgery, ultrasonic surgery, and tissue removal by high-energy radiation beams are now available as options in selected cases. Additional research is needed to determine how people—particularly children—should be screened and selected for surgery.

Brain injury and epilepsy

Another area of current research focuses on what happens to the brain when it is injured. Recent studies suggest that seizure-induced brain damage may lead to a chronic epileptic state. Drugs and therapies are needed to promote brain cell survival and to prevent seizures from producing more seizures. Research is also needed to determine why repeated seizures cause brain injury and more severe seizures in some people, but not in others.

Advances in neuroimaging techniques

Recent advances in neuroimaging allow scientists to see in detail the internal structures of the brain. Emerging techniques now permit the investigator to observe chemical changes in brain tissue leading up to and during a seizure. These techniques will allow significant progress to be made in pinpointing the causes of epilepsy and possibly identify a cure. Progress in imaging techniques may allow scientists to accurately predict seizure occurrence in high-risk patients and intervene.

Gene identification

One area of research that holds great promise is the identification of the genes responsible for predisposition to certain types of epilepsy. Research has identified several genes for childhood epilepsies in the last few years. Gene identification can allow doctors to predict whether an individual or his children are likely to develop epilepsy. In addition, gene identification can also help to isolate the missing critical protein in the deficient gene. In combination with advances in gene therapy, this

genetic approach will allow replacement of the missing protein or repair of the gene. Such advances will not only suppress seizures, but will cure this type of epilepsy.

FISCAL 2000 FUNDING RECOMMENDATIONS

The Epilepsy Branch within the National Institute for Neurological Disorders and Stroke is vital to continuing the fight against epilepsy and currently funds many valuable projects. The promise of future breakthroughs in epilepsy research can only be achieved through increased funding for epilepsy research and prevention programs. The Foundation urges Congress to increase the federal commitment to epilepsy research by allocating sufficient funding for the NINDS and Centers for Disease Control.

National Institutes of Health.—The Foundation supports Congressional efforts to double the NIH budget over 5 years and is seeking a 15 percent increase for fiscal 2000 ($17.9 billion).

National Institute for Neurological Disorders and Stroke.—The Foundation supports a 15 percent increase for NINDS in fiscal 2000 ($916.5 million), consistent with the efforts to double NIH research funding over 5 years.

Epilepsy Medical Research.—The Foundation urges Congress to support a major expansion of epilepsy research within NINDS. In 1998, NINDS spent $63.8 million dollars on epilepsy research. We are seeking a commitment to triple that amount over the next few years.

CENTERS FOR DISEASE CONTROL EPILEPSY PROGRAM

As directed by Congress in 1993, the CDC launched its epilepsy program within the National Center for Chronic Disease Prevention and Health Promotion. Focusing on early detection and effective treatment of epilepsy, the epilepsy program targets its outreach and education efforts on consumers, health professionals, and health systems including managed care plans and Medicaid.

With one in ten Americans likely to experience a seizure in their lifetime, epilepsy represents a major public health problem. To attack this problem effectively, the public health community must work with the epilepsy community to develop strategies for preventing epilepsy as well as strategies for overcoming barriers to optimal health and function for persons with epilepsy. A corresponding national public health campaign must be waged to support and enhance these efforts.

Recently, the CDC, in partnership with the Epilepsy Foundation, the National Association of Epilepsy Centers, and the American Epilepsy Society, sponsored a conference to set objectives for improving the health of persons with seizure disorders. The conference brought together experts in the field of epilepsy treatment and research together with patients and families affected by epilepsy and seizure disorders. Recommendations were developed in the areas of early detection and treatment, epidemiology and surveillance, and health communication strategies. Together, these recommendations will move our nation much further in reducing the public health burden imposed by this disorder.

CDC Epilepsy Program.—We cannot achieve the objectives of the conference with the current level of funding, approximately $700,000. Thus, we recommend a modest federal investment of $5 million as the first step in implementing the recommendations from the conference.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

YOU ARE A TARGET

Chances are heart attack or stroke will be the death or disabler of you or a loved one. You are not alone. Heart attack, stroke and other cardiovascular diseases remain America's No. 1 killer and a main cause of serious disability. Cardiovascular diseases account for nearly 1 of every 2 deaths in the U.S.

The American Heart Association is dedicated to reducing death and disability from heart attack, stroke and other cardiovascular diseases. We commend this Committee's historic fiscal year 1999 funding increases for the National Institutes of Health and the Centers for Disease Control and Prevention. But, we are concerned that our government is not devoting sufficient resources for research and prevention of America's No. 1 killer—heart disease—and to our country's No. 3 killer and a leading disabler—stroke.

HOW YOU CAN MAKE A DIFFERENCE

Now is the time to capitalize on progress in understanding heart attack, stroke and other cardiovascular diseases. Promising, cost effective breakthroughs in research and prevention are on the horizon. We challenge our government to continue increases to double funding by year 2003 for NIH heart and stroke research and to translate research into effective clinical and community initiatives. This will help cut health care costs and improve quality of life. For fiscal year 2000 we urge you to do the following.

—Appropriate a 15 percent increase over fiscal year 1999 funding for the overall NIH, the next step toward the goal of doubling the budget by year 2003. This goal is echoed by groups such as Research!America and the Ad Hoc Group for Medical Research Funding.

NIH research provides cutting-edge treatment and prevention strategies, cuts health care costs, creates jobs and maintains America's status as the world leader in biotechnology and pharmaceuticals industries.

—Provide a 15 percent increase over fiscal year 1999 funding for NIH heart research and stroke research.

Heart and stroke researchers are on the brink of advances that could pave the way to prevention and even a cure so you or a loved one will be spared pain and suffering from heart disease and stroke.

—Allocate $45 million to expand the CDC Cardiovascular Health Program.

We must make our science real and applicable through community interventions that encourage Americans to make heart healthful lifestyle choices.

STILL NO. 1

Heart attack, stroke and other cardiovascular diseases have been America's No. 1 killer since 1919. Nearly 60 million Americans of all ages suffer from one or more of these diseases. Millions of Americans have major risk factors for these diseases—about 50 million have high blood pressure, 39 million have elevated blood cholesterol (240 mg/dL) and 48 million smoke. As the baby boomers age, the number of Americans afflicted by these often disabling diseases will increase substantially. Cardiovascular diseases put an enormous burden on our economy. Americans will pay an estimated $287 billion for cardiovascular medical costs and lost productivity in 1999. These diseases constitute 4 of the top 5 hospital costs for all payers, excluding childbirth and its complications, and 4 of the top 5 Medicare hospital costs. Heart disease is the leading cause of premature, permanent disability among American workers, accounting for nearly 20 percent of Social Security disability allowances.

HEART AND STROKE RESEARCH BENEFITS ALL AMERICANS

Thanks to advances in addressing risk factors and in treating cardiovascular diseases, more Americans are surviving heart attack and stroke. Heart and stroke research and prevention breakthroughs are saving and improving lives of your friends and those you love every day. You and your family have benefited directly from heart and stroke research. Several cutting-edge examples follow.

—*Emergency Cardiac Care*.—Each day about 685 Americans suffer sudden cardiac arrest. A particular sequence of actions known as the "chain of survival" offers hope for these people. Early use of both breathing and chest compression techniques of cardiopulmonary resuscitation and delivery of a powerful electrical shock to re-start the heart are critical to restore life. Each minute of delay in returning the heart to its normal pattern decreases chance of survival by 10 percent. The AHA's Operation Heartbeat Program, alone, estimates that 100,000 lives can be saved if automatic external defibrillators (AEDs) were more widely available.

—*New Surgical Heart Techniques*.—Research has revolutionized surgical techniques in cardiology. You probably know someone who has benefited from research breakthroughs called heart bypass surgery and percutaneous transluminal coronary angioplasty (PTCA). Patients who experience conventional bypass surgery to improve blood flow to the heart require several weeks to recover. Those who experience the new "keyhole" or "minimally invasive heart bypass surgery" need only several recovery days. Surgeons operate via a three-inch incision. Keyhole surgery can provide an alternative for the growing number of Americans who endure the traditional surgery to eliminate chest pain, increase ability to exercise and reduce fatigue and need for medicine. In 1996, about 843,000 patients benefited from bypass surgery and PTCA to improve blood supply to the heart.

—*Surgery to Reduce Risk for Stroke*.—When the main artery to the brain becomes blocked, in many cases surgeons now can remove the buildup of plaque to prevent stroke. It benefits not only stroke survivors, but also helps some patients who experience early stroke symptoms and may help prevent stroke in some patients.

—*State-of-the Art Life-extending drugs*.—Research has produced amazing new drugs to help prevent and treat heart attack and stroke. Cutting-edge drugs to control blood pressure and cholesterol are more effective than ever in saving lives and enhancing life quality of millions of Americans. Revolutionary "clotbuster" drugs can reduce disability from heart attack and stroke by dissolving blood clots causing the attack. Use of t-PA within three hours of the onset of a stroke, can stop progression of clot-caused stroke and reduce chances of permanent disability by 33 percent, saving health care costs. T-PA offers hope for the estimated 1.1 million Americans who are expected to suffer a heart attack and 450,000 at risk of a clot-caused stroke in 1999.

So Americans can continue to benefit from these types of breakthroughs, we support doubling of the overall NIH budget by year 2003. The AHA recommends an fiscal year 2000 appropriation of $18 billion for the NIH as the next step toward that goal. AHA has a special interest in individual NIH institutes that relate directly to our mission. Our funding recommendations for these institutes and programs follow.

HEART RESEARCH CHALLENGES AND OPPORTUNITIES FOR NHLBI

These aforementioned advances and other achievements have been made possible by more than 50 years of AHA-sponsored research and more than a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. Thanks to research, no longer does a heart attack or stroke necessarily mean immediate death. But they can mean permanent disability, requiring costly medical care and loss of productivity and quality of life.

The AHA urges this Committee to double the NHLBI budget by year 2003. As the next step toward reaching this goal, we recommend an fiscal year 2000 appropriation of $2.051 billion for the NHLBI, with $1.216 billion for heart and stroke-related research. A funding level of this amount will allow NHLBI to expand existing programs and invest in promising new initiatives. Several challenges and opportunities follow.

—*Congestive heart failure*.—About 4.6 million Americans suffer from congestive heart failure. This often-disabling condition remains America's fastest growing heart disease. It is the main cause of hospitalization for those ages 65 and older. During the past 18 years, hospitalizations for this condition have more than doubled. For many, relatively simple tasks like making the bed or preparing breakfast can be so fatiguing that the rest of the day has to be spent in bed. A heart transplant is the only lifesaving therapy for patients with advanced heart failure. More research is essential to understand how and why the disease occurs and how it can be treated and prevented. Promising areas need more study. These include mechanical assist devices; use of animal hearts for transplant; transplant of healthy heart cells and the role of programmed cell death in development of congestive heart failure. Increased funding could lead to new methods for treatment and prevention.

—*Angiogenesis or control of new blood vessel growth*.—In the next century many of the 21 million Americans with heart disease may be routinely treated with a genetically engineered therapy that stimulates growth of new heart blood vessels. Creating a "natural bypass," these new vessels would help restore blood flow to the hearts of people whose arteries are obstructed by fat-laden plaque. Angiogenesis may become an adjunct to other therapies for heart disease, including low saturated fat diets, exercise, smoking cessation, and, if appropriate, medications such as cholesterol-lowering drugs and surgical procedures of heart bypass surgery and angioplasty. This exciting new technique could provide an alternative for patients who cannot endure conventional bypass surgery. Recent research suggests that blocking growth of certain tiny arteries through similar techniques may slow plaque growth. But, more funding is needed to support research to design approaches to translate knowledge of angiogenesis for use in preclinical studies and clinical applications.

—*Advanced Non-Surgical Imaging Technology*.—An estimated 1.1 million Americans will suffer a heart attack and about 600,000 will suffer a stroke in 1999. Most of these heart attacks and strokes will be triggered by blood clots unleashed by plaque obstructions in blood vessels. The clots, which are formed when the plaque obstructions rupture, block blood flow to the heart and brain, causing a heart attack or stroke. In 1998 scientists described preliminary find-

ings on how magnetic resonance imaging (MRI) can detect these high-risk plaque obstructions. If this technology proves effective in identifying unstable plaque obstructions in blood vessels, it will provide a new way for cardiologists to diagnose people at high risk of suffering a heart attack or stroke and to start treatment to help stabilize the obstruction or reduce chances that a blood clot will form if a plaque ruptures. Other areas of cardiology could benefit from this technology, including guiding local injections for angiogenesis, tracking and delivering modified cells in the blood vessel system and performing biopsies. Increased funding in this area could revolutionize the approach to patient care.

—*Heart attack, stroke and other cardiovascular diseases in women*.—Cardiovascular diseases are a main cause of disability and the No. 1 killer of American females, killing more than 500,000 each year. These diseases kill more females than the next 16 causes of death combined. They kill more females than males. More than 1 in 5 females live with consequences of cardiovascular diseases. The clinical course of cardiovascular disease is different in women than in men and diagnostic capabilities are less accurate in women than in men. Once a woman develops a cardiovascular disease, she is more likely than a man to have continuing health problems and is more likely to die from it. These diseases are largely unrecognized by both women and their doctors. Additional funding is needed to allow the NHLBI to expand research on cardiovascular diseases in women, including studies to develop safe, efficient and cost-effective diagnostic approaches for women, and to create informational and educational programs for patients and health care providers on cardiovascular diseases risk factors as authorized under Public Law 105–340, the Women's Health Research and Prevention Amendments of 1998.

STROKE RESEARCH CHALLENGES AND OPPORTUNITIES FOR NINDS

Stroke is a major cause of permanent disability and America's No. 3 killer. America's estimated 4.4 million stroke survivors often face debilitating physical and mental impairment, emotional distress and overwhelming medical costs. About 20 percent required help walking and 71 percent had impaired capacity to work when examined an average of seven years later. An estimated 600,000 Americans will suffer a stroke in 1999. Considered a disease that strikes our grandparents, stroke also afflicts newborns, children and young adults. More Americans are dying from stroke than ever before.

We urge a doubling of the stroke research budget through the National Institute of Neurological Disorders and Stroke by year 2003. An fiscal year 2000 appropriation of $1.034 billion for the NINDS, with $111 million for stroke research, the next step toward the goal, will allow NINDS to expand studies and start new research to prevent stroke, protect the brain during stroke and enhance rehabilitation. Some challenges and opportunities follow.

—*Brain imaging*.—Imaging plays a critical role in evaluating stroke patients, providing non-invasive diagnosis, treatment assessment and prediction of recovery. Research is required to combine knowledge from diverse imaging techniques to enhance data on brain activity. Resources are needed to develop imaging to quickly diagnose some 450,000 stroke patients a year who may benefit from t-PA. Refined imaging technology has broad application for other brain disorders.

—*Genetics of Stroke*.—Stroke often has a genetic element. Research has identified a gene linked to stroke caused by a blockage. Other studies have identified genetic risk factors associated with stroke. More funding is needed to learn ways to stop mechanisms used by defective genes to cause stroke.

—*Stroke Clinical Trials*.—Basic research has progressed to the point where clinical studies are crucial in advancing the prevention and treatment of stroke. Clinical trials are investigating drug therapies and surgical interventions and assessing the needs of special populations at high risk of stroke. Increased funding for clinical trials could produce cutting-edge stroke treatment and prevention.

—*New Stroke Drugs*.—Increasingly, promising new medications to treat stroke will become ready for evaluation in patients. They include drugs to restore blood flow to the brain, protect cells from dying when stroke is in progress and prevent injury when blood flow is restored. Increased resources are critically needed to improve and test these drugs in the treatment of stroke.

—*Public and Professional Education for Stroke Treatment*.—T-PA is the first effective emergency treatment for clot-caused stroke. The AHA and eight other national organizations are working with the NINDS to increase public awareness of stroke symptoms and appropriate emergency action. They are also striving to develop systems to make t-PA readily available to appropriate patients.

When these systems are fully implemented, stroke treatment will change from supportive care to early brain-saving intervention. More funding is urgently needed to address challenges in educating the public about stroke symptoms and the need for prompt treatment and in assuring appropriate response systems are in place in communities. More health care professionals must be educated about t-PA and the need for rapid response.

RESEARCH IN OTHER NIH INSTITUTES AND CENTERS BENEFITS HEART & STROKE

National Institute on Aging defines how the aging process contributes to cardiovascular diseases, a main disabler and No. 1 killer of older Americans. An fiscal year 2000 appropriation of $50.6 million for cardiovascular research will allow continuation of studies and expansion into promising areas.

National Institute of Diabetes and Digestive and Kidney Diseases studies help in reducing cardiovascular disease death and disability. We advocate an fiscal year 2000 appropriation of $1.15 billion for the NIDDK to advance research to help diabetics, ⅔ of whom will die from heart disease or stroke.

National Institute of Nursing Research studies play a key role in promoting self-care and patient education. NINR research is critical to primary and secondary prevention of heart attack, stroke and other cardiovascular diseases. We advocate an fiscal year 2000 appropriation of $80.6 million for the NINR.

Animal research is critical for heart and stroke research. AHA supports an fiscal year 2000 appropriation of $638.041 million for the National Center for Research Resources to help institutions and researchers obtain animals and provide humane care for them. Increased resources will fortify animal research, help correct deficiencies in research animal resources and strengthen nationwide Clinical Research Area Centers and Biomedical Technology and Infrastructure Areas.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

AHCPR plays a key role through establishment of practice guidelines and conduction of outcomes research. Practice guidelines and outcomes research help insure that high quality and cost-effective medical services are provided. Their guidelines on stroke rehabilitation have received important attention from practitioners. We concur with the Friends of AHCPR's recommendation of an fiscal year 2000 appropriation of $225 million for the AHCPR.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Prevention is the best way to protect health of Americans and lessen the enormous financial burden of disease. Your commitment cannot stop at the laboratory door. You must fund the work that brings research into the places where heart disease and stroke live—the towns and neighborhoods that populate America.

The CDC builds the bridge between what we learn in the lab and how we live in our communities. CDC sets the pace on prevention. The AHA recommends an fiscal year 2000 appropriation of $3.4 billion for the CDC.

As a result of the efforts of this Committee, CDC's Cardiovascular Health Program began in fiscal year 1998 with 8 states now receiving funds to implement state-based cardiovascular disease prevention and control programs. In 1997, CDC released a report outlining what the nation's priorities should be in the area of chronic disease prevention. The report titled, "Unrealized Prevention Opportunities: Reducing the Health and Economic Burden of Chronic Disease," said "strong chronic disease prevention programs should be in place in every state to target the leading causes of death and disability . . . and their principal risk factors." Until the fiscal year 1998 appropriations initiated a comprehensive Cardiovascular Health Program, the CDC-administered Preventive Health and Health Services Block Grant was the only source of federal funding to states for targeting the No. 1 killer in every state.

Steps taken to create the Cardiovascular Health Program delight the AHA. An fiscal year 2000 appropriation of $45 million for the Cardiovascular Health Program will allow CDC to expand this program to 14 more states and to further strengthen the foundation for a nationwide program.

The WISEWOMAN Program uses the framework of CDC's National Breast and Cervical Cancer Early Detection Program to screen women for cardiovascular disease risk factors. An appropriation of $15 million will allow CDC to support up to 13 states for participation in WISEWOMAN.

The Preventive Health and Health Services Block Grant has been a vital resource for states in their efforts to fight heart disease and stroke. The AHA recommends an fiscal year 2000 appropriation of $255 million for the PHHSBG. We urge the Committee to address, as the "Unrealized Prevention Opportunities" points out, the need to target risk factors. The AHA supports CDC's efforts to build:

—a comprehensive nutrition and physical activity program with an appropriation of $15 million;
—a national program to prevent tobacco use, including a national public education campaign to reduce youth access to tobacco products, through the CDC's Office of Smoking and Health with an fiscal year 2000 appropriation of $242.5 million; and
—a comprehensive school health education program with an appropriation of $25 million.

Coupled with a nationwide Cardiovascular Health Program, these initiatives will advance the fight against heart disease and stroke. We urge you to make cardiovascular health a national priority.

ACTION NEEDED

Significantly increasing resources for research and community intervention programs will allow this nation to make great strides in the battle against heart attack, stroke and other cardiovascular diseases. Our government's response to this challenge will help define the health and well being of our citizens—including your constituents, yourself and those you love—into the next century.

PREPARED STATEMENT OF JOHN D. AQUILINO, JR.

On behalf of my son, John, his five-year-old brother, Tommy, our family and friends, I want to thank the Chairman and members of the subcommittee for allowing me to submit testimony in support of funding of the National Heart, Lung, and Blood Institute and it's on-going heart-research programs.

As you have heard and will continue to hear until the men and women working in this field conquer the many complex problems in this area, physical problems of the heart are and continue to be the number one killer of our people and the cause of or most common birth defect.

I repeat the never too often repeated message that heart disease is a major problem, not only with our age group, but also with our children.

Congenital heart defects are the major cause of birth-related infant deaths in the United States affecting 32,000 newborns each year. Of that number more than 2,300 babies die before their first birthday. And one million Americans like my son, Johnny, lives with its consequences.

Johnny is nine years old now. He finished his first basketball season and is getting ready for coach-pitch baseball at St. Jerome's School in Hyattsville, Maryland. He is, I believe, the oldest child in this area and maybe the East Coast with hypoplastic left heart. His left ventricle, the major pumping chamber in his heart, never formed.

I'd like to say from the start the Johnny and I thank your for your leadership and support for funding NIH and NHLBI. While NHLBI's funding decreased by 2.3 percent in constant dollars from fiscal year 1988 to fiscal year 1998, I ask that you follow the American Heart Association recommendation of putting $2.05 billion dollars into the Institute and doubling NIH's funding by the year 2003.

This support is critical. I live for the day when the work of men and women at the Institute allow my son to clone a new healthy heart from his own DNA. I will not slow my advocacy for this research until that and similar research applications are available to all children no mater their land or origin or economic status.

I confess that when I tell Johnny's story my eyes overflow and my voice cracks. Today, I want to take a slightly different approach.

The years of standing in hope while Johnny underwent three open heart surgeries and other invasive procedures caused me to look to the fate of children beyond my son. In 1994, after my son's third open-heart surgery, I attended the Convention on International Trade in Endangered Species, commonly called CITES. I listened to the plight of rural African villagers. I thought of Johnny's fate if we had been born there.

This past March 27–30, I was in Iceland attending a meeting of indigenous people and nations whose traditional diets include marine mammals such as whales. There were native people from Washington State, Alaska and British Columbia. Inuits from Canada, Greenland, Russia and other circumpolar regions were there. Maoris from New Zealand and people from the Polynesian Island Kingdom of Tonga as well as representatives from Caribbean Island states all echoed the same message.

Heart disease and diabetes are afflicting their people because government and international policies took the diet from them.

Beyond that issue, my thoughts went to their children. Those born with conditions like Johnny's simply do not have a chance of surviving. And again, I thought, what

if Johnny and I were born Inuits? He would no be here today. I would be a lone voice across the ice flows asking why?

The work you are funding at NIH and the NHLBI affect us all. The fruits of their research will and should be the gifts to the parents and children of other nations and other people most truly reflective of our country and our heritage.

Again, I thank you for your leadership and support.

PREPARED STATEMENT OF ERIN BOSCH

Mr. Chairman, honorable members of the Committee, I am honored to have the opportunity to speak to you today. My name is Erin Bosch. Today, I am here to testify on behalf of not only myself, but also, the 32,000 children in the United States who are born with congenital heart defects each year.

Most of us are aware that heart disease is the No. 1 killer and a leading cause of disability in adults in this nation. But few recognize that heart defects are the most common birth defect of the newborn. Of the 32,000 children born each year with heart defects, around 2,300 die before their first birthday. The rest of us live with the consequences of heart disease. Many have their lives cut short from heart failure.

Thanks to the past funding for heart research about 1 million Americans born with heart defects are alive today. While we are grateful for each day that we are alive, we, unlike other healthy children, have not been able to experience what it is like to run the length of the soccer field without struggling for our next breath, nor have we experienced the thrill of scoring the winning basket for our school basketball team. Some of us are hardly able to walk a flight of steps without needing to rest.

I was born with a genetic heart disease called Hypertrophic Obstructive Cardiomyopathy. This disease has caused my heart muscle to overgrow and block the blood flow in and out of my heart. It also effects the valves of my heart, causing the blood to back up in the wrong direction. Along with this disease comes a high risk for heart attack. Dangerous heart rhythms often cause sudden cardiac death.

Two years ago in October, I was at the Mayo Clinic having open heart surgery. The procedure, called a septal myectomy, was designed to shave away a portion of the heart muscle that causes the obstruction. This procedure was originally pioneered at the National Institutes of Health's National Heart, Lung, and Blood Institute, and was my last resort aside from transplant for a healthier life.

It was funding that this Committee provided that allowed this type of successful research. Without this funding the option of a healthier lifestyle would not have been possible for me. Other research dollars have successfully contributed to the development of pacemakers and intra-cardiac defibrillators that other children and I depend on. Current research is being forged for patients with HCM for less invasive therapies with hopefully long-term success. Committed research dollars are essential for this research to continue.

I am one of the lucky ones. My surgery was successful and after one month at the Mayo Clinic I was able to return home. My struggle, however, is not over. My physicians only hope my heart muscle remains stable so no further procedures will be necessary, but they just do not know. There have been some advances for children like me, although many still die prematurely.

Most people think heart disease is a problem that only affects older people. But, I am living proof they are wrong. According to recent studies, 36 percent of young athletes who die suddenly have undiagnosed Hypertrophic Cardiomyopathy.

Presently, there are at least 35 different types of recognized congenital heart defects effecting the newborn population. Some can be corrected surgically—others cannot yet be repaired and these children die. One of these children might one day be your child or grandchild.

I have great faith in the determination of our scientific researchers who work day and night to find new treatment methods for those who suffer with illness and disease. I also have great faith in you as the doorkeepers of governmental funding to provide the necessary funds for children who have been born with heart defects.

Thank you for the opportunity to speak with you today. I am confident that you will not forget me and the other young people like me who depend on you for funding this vital research. We too, like you, desire to live long, productive lives.

PREPARED STATEMENT OF WARREN GREENBERG, CHAIRMAN ON LOBBYING/LEGISLATION, THE MENDED HEARTS, INC.

My name is Warren Greenberg. I am a professor of health economics and of health care sciences at The George Washington University. I am married and have a 24-year-old daughter.

I advocate an increased appropriation for the National Heart, Lung, and Blood Institute. I am a victim of heart disease and as a beneficiary of the efforts of medical researchers to overcome this disease. I might also add that I am a member of Mended Hearts, Inc., a support group of 24,000 members throughout the United States. I have been appointed lobbying and legislation chairperson of that group—a volunteer position.

I am 55 years old. I was born with aortic stenosis, a narrowing of the heart valve. Throughout my entire life I have lived with heart disease, often incredibly severe.

When I was in my early teens, my physicians did not allow me to play high-school inter-mural sports, although I was a fine young athlete. At the age of eighteen I was told not to play ball under any circumstances. In my early 20s I was told to climb no more than two flights of stairs. By my early and mid-thirties I began to climb steps more and more slowly, often pausing to rest. I never carried an attache case home from work. It was too heavy. I would often balance a large book on my hips, rather than carrying it outright, in order to blunt the weight. I would walk two or three blocks on a level street to avoid going up three or four steps at the end of particular blocks. I could barely lift my newborn child; I could not help my wife take in the grocery bags.

On May 7, 1982, at the age of 39, I had open-heart surgery at the Cleveland Clinic to replace my diseased valve with the valve of a pig. After my six-week recuperative period I was amazed to find that not only was I able to walk, but was also able to play tennis, to jog, and to exercise. I was able to live a normal life.

By August 1988, however, my new valve had failed. On August 31, I again had cardiac surgery at the Cleveland Clinic to replace the failed pig valve with an artificial plastic valve, known as the St. Jude's valve. I am again able to live a relatively normal, very productive life. And I am deeply thankful for it.

I still take a blood-thinning medicine, coumadin, which helps prevent clots on my new valve. At the same time, because of the medicine, I must be cognizant and careful of excessive bleeding. In 1983 I contracted bacterial endocarditis, an infection of the heart valve, from dental surgery which kept me in the hospital for six weeks. Whenever, I have dental work, I now get intravenous penicillin to protect me against such infections. I realize that my valve, as a mechanical device, may fail at any time in the future.

For nearly 17 years, thanks to the fruits of medical research, I have been able to travel abroad at least once a year, to jog in the park, to be a productive author of many scholarly articles and a number of books on the health care economy. I have been quoted often on my views of the U.S. health care system and have made many television appearances. If it were not for the advances in research leading to improved techniques in open-heart surgery, I would not have seen my fortieth birthday. I would not be able to look forward to a life of many rewards and enjoyments.

As an economist. I observe continually the link between monetary resources and the development of innovation and technology. Health care research, and cardiovascular research in particular, is no exception. I also understand as an economist that there are always competing uses for appropriated monies. However, cardiovascular diseases last year killed nearly 960,000 Americans, about 154,000 of whom are under age 65. Despite advances in medical research, these diseases remain the number one killer in the United States and a leading cause of disability. From my personal perspective and for those in Mended Hearts Inc. and others in the United States who have heart disease or will get it in their lifetime, consistent with congressional resolutions for the National Institutes of Health, I ask for a doubling of National Heart, Lung, and Blood Institute budget by year 2003. To reach this funding goal, I advocate a fiscal year 2000 appropriation of $2.051 billion for the NHLBI to help reduce further the incidence and degree of heart disease.

PREPARED STATEMENT OF FRANCIS T. VENTRE, PRESIDENT, MONTGOMERY COUNTY (MD) STROKE CLUB

My name is Francis T. Ventre. I am president of the Montgomery County [MD] Stroke Club, a nonprofit organization for stroke survivors and caregivers, mostly family members. This club consists of some 425 members as well as 100 professionals—physicians, therapists, hospitals, retirement homes, units of government and other caregivers.

Our members range in age from the twenties to the eighties. Some manifest little visible signs of stroke. Others either have lost the ability to speak or need assistance to walk, dress, bathe and eat. More than 1 million in this land have disabilities from stroke.

Let me tell you about my stroke. I was professor of architecture and city planning at Virginia Tech since 1983. In 1988, Macmillan signed me up to write on the subject of "building regulation" for The Dictionary of Art, the 34-volume exposition with 6,700 contributors it was planning to publish.

In February 1990, when I was swimming at Virginia Tech's War Memorial pool, I was struck with a transient ischemic attack [TIA], or a mini-stroke. Two days later, at North Carolina Baptist/Bowman-Gray Hospital in Winston-Salem, I suffered a major stroke, a "left cerebral infarct in the middle cerebral artery distribution following the spontaneous dissection of the right internal carotid artery during an angiogram." I was left with an "mild Broca's aphasia with verbal aphasia": [or a "language problem"] and a "residual right hemiparesis," [or my right arm didn't work]. There was my stroke!

I was home when I thought of the "building regulations" article I had to write, so I resumed. The Dictionary of Art came out in October, 1996, and the New York Times Book Review came out in August 24, 1997. My "building regulations"—along with two others—as cited as "those sections among the most memorable precisely because they're unconventional, hence thought-provoking." That's my story!

Stroke, the third leading cause of death in the United States, strikes 600,000 Americans each year, killing nearly 160,000. Stroke is the leading cause of permanent disability in the United States. Thanks to medical research, today, there are about 4.4 million stroke survivors in the United States and I am one of them.

What do stroke survivors face? They face years of severe physical and mental impairment, loss of memory, cognitive skills, personality disorders, emotional distress and overwhelming medical expenses. Stroke will cost this nation an estimated $45 billion in medical expenses and lost productivity in 1999. My own expenses were $18,000 at the Bowman Gray Hospital in Winston-Salem plus many more thousands of dollars at rehabilitation, including physical therapy, occupational therapy and speech-language pathology and many more thousands of dollars at the National Rehabilitation Hospital in Washington, D.C. and the Treatment and Learning Center in Rockville, Maryland.

There is one thing that I want you to know about National Institute of Neurological Disorders and Stroke researcher John Marler, M.D. It came from the November 24, 1997 copy of USA TODAY, headlined "OVERHAUL URGED FOR HANDLING OF STROKES," upgrading stroke to a "time-dependent, urgent medical emergency." The report, "Rapid Identification and Treatment of Acute Stroke," describes how physicians, emergency care personnel and the public should respond to the finding that a drug called tissue plasminogen activator or t-PA, destroys the clots that dam up arteries, restoring blood flow to the brain. The drug t-PA, to be effective, must be given within three hours of the initial symptoms. Given in time, the drug improves the patient's chances of having minimal or no disability by 33 percent three months after surviving a stroke.

I wish that the t-PA were available in 1990.

PREPARED STATEMENT OF RICHARD E. BUZBEE

I am Dick Buzbee, of Hutchinson, Kansas, and I am one of the grandfathers of Anne Marie Buzbee. I'm speaking on behalf of her family.

Anne Marie's mother, Sally Buzbee, is a journalist with the Associated Press here in Washington, D.C. Anne Marie's father, John Buzbee, is a foreign service officer with the State Department.

First: I want to report how Congress' foresight in supporting heart research affected little Anne Marie and our family.

Second: I will suggest that a bold emphasis on further research will extend national benefits even beyond the potential savings of all the 32,000 babies who have been born annually with heart defects. Anne Marie was one of those 32,000 babies in 1997. She was one of the about 3,200 babies in 1998 who did not survive.

However, we had 7½ months with her. Those 7½ months were made possible largely by Congress' commitment to research that has continued since 1948. Because of that research, the family knew 4 months before her birth that Anne Marie would face profound heart, hand, and other physical defects.

With that knowledge, the doctors, nurses, and other specialists at Georgetown, and Children's National Medical Center were able to deliver safely Anne Marie, and

soon thereafter complete the first of what would be many complicated operations and tests—all made possible by federal research support.

The doctors never discovered the source of her problems. But the National Heart, Lung, and Blood Institute continues to probe for answers that some day will tell us what causes congenital heart abnormalities.

Anne Marie traveled a lot during her 7½ months. Much of it was within hospitals and going to and from hospitals. She loved to travel. In her stroller on the sidewalk in the Friendship Heights neighborhood, she delighted in looking up at the leaves, and generally insisted in keeping moving. But once, when her dad took her over to a neighborhood coffee shop, she sat patiently in the stroller next to him, contenting herself with her pacifier while he savored a cup of coffee and a brief, worry-free moment with her.

A year ago, as the cherry trees were beginning to bloom, we bundled her up, and her mom and dad drove us to the Tidal Basin so she could take her first stroll under the cherry blossoms. However, we were so excited about taking her for a stroll in her stroller, that when we arrived at the cherry trees, we discovered we'd forgotten to pack the stroller. No matter. She liked to be held, too. There was no shortage of volunteers.

Indeed, Anne' parents and grandparents spent many hours holding her, and rocking her, playing "itsy bitsy, spider," and "the wheels on the bus go round and round." Anne especially loved books. Even at 6 and 7 months, even when she felt poor, or was in the hospital, she would stare at the pictures in her books-—and put out her hand to turn the page when she wanted to see more. Especially when the book was about "Bloodhound Ben."

We learned a lot from Anne.

She taught us that neither medical science nor love can fix all problems, but love and medical science can enrich all lives with undying reminders—not of what might have been, but what will be, so long as we embrace each other today and tomorrow.

Her family today stretches from the district here, to Half Moon Bay in California, and from Anchorage to Baton Rouge. We will carry a part of her, and she will be a part of us, for we are richer today than we were before we met Anne.

That is the final point I want to make: As our family is enriched, so are we all collectively.

A nation that seeks so vigorously to help little Anne with HER heart problems will most assuredly find that ITS collective heart has been strengthened, so that all of us will never again be quite the same.

And with an enduring commitment to research—and the eloquence of a search that is worthy of America today—someday—thousands of other little Annes will be able to grow up and contribute to the nation that so confidently invested in their future.

We will all be better for it—and not least among us the dads and grandads who will have many opportunities to remember to bring along the stroller when they take the baby for the stroll under the cherry blossoms.

Prepared Statement of Miriam Feder, Executive Director, Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

Mr. Chairman and Members of the Subcommittee: My name is Miriam Feder. I am the Executive Director of the Dystrophic Epidermolysis Bullosa Research Association (DebRA) of America. The members of DebRA wish to express sincere thanks to you for this opportunity to submit written testimony regarding the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS).

The families of America whose lives have been devastated by epidermolysis bullosa wish to thank you and the members of the Subcommittee for your extraordinary support of biomedical research and the National Institutes of Health. We are very gratified that you have heard our voice and very grateful for your support of a 15 percent increase in NIH funding for fiscal year 1999. Your continued and enthusiastic support for the National Institutes of Health (NIH) has created an environment that has produced extraordinary biomedical advances that will make a cure for EB possible in the near future. We are also grateful for the translation of the technology which is helping to ameliorate the pain and suffering until a cure has been found. These technological miracles would not be available if not for the basic science research funding from NIH through universities and independent research institutions.

This year, DebRA joins our medical and patient colleagues in urging the Congress to support a second 15 percent increase for the NIH, the second installment of a five-year plan to double the NIH budget. A 15 percent increase would provide $18

billion for the NIH, money that will be put to excellent use by scientists looking to address the many challenges that EB patients still face. In addition, we urge the Subcommittee to provide $354 million for the NIAMS in fiscal year 2000. The diseases investigated by this institute have a substantial impact on quality of life, use of health care resources, and the nation's economy.

Again in 1999, I must regrettably report that too many children and young adults have died of the effects of EB in this past year. The great majority of these deaths are from metastatic skin cancer. However thousands of children and their families affected by EB recognize and are grateful to you and this committee for they will know that NIAMS funded EB research has made a cure for EB more than a distant dream. The establishment of the EB Registry in 1980 remains a model for all rare disease registries. It is the foundation upon which the phenomenal progress on EB research rests and has been cited as the success story clearly illustrating what NIH funding has successfully accomplished. The creation of this registry, with funding from NIAMS, is responsible for the promise of gene therapy, advancing techniques of wound healing and burn treatment, and understanding the mechanisms of EB blistering and vesicant injury.

EB is a group of inherited disorders in which genetic defects produce blistering of the skin and mucous membranes and creates deep wounds. It is disfiguring, severely disabling and often fatal; wreaking dire emotional and financial costs. EB may have dire effects on many other systems of the body and complications including malnutrition, hand and joint deformities, chronic anemia and early death due to respiratory failure, heart failure and cancer. Many babies die before their first birthday.

I would like to relate to you the story of two remarkable families who have been challenged by this devastating disorder.

Dana Marquardt was born on April 27, 1971, her mother did not hear the anticipated "congratulations" because the neonatal/obstetric team was concentrating on the sacs of fluid which hung from the infant's hands and feet and the sloughing of skin from her entire tiny body. After three agonizing months these young parents brought their bandaged baby home with the mysterious diagnosis of epidermolysis bullosa (EB).

For Dana and the thousands of other Americans affected by this dreadful genetic disease; the daily care consists of changing her bandages and draining the fluid from blisters that result from the slightest friction to her fragile skin. Antibiotic ointment is then applied to the blisters and open wounds to lessen the amount of infection. She then has to cover the lesions with non-stick pads and wrap gauze bandages around her arms, legs and some times her whole body. She must secure the bandages with a special tape until the next day or until her soaking bath then repeats the process. Dana's mother assists her with most of her routine because of the extent of her disability. Dana's father navigates the sea of red tape associated with denied insurance reimbursements for bandages, antibiotic ointments and specialized medical and surgical care.

In Dana's own words, she describes living with EB: "Living with epidermolysis bullosa is like fighting a losing battle with my own body. Just when I begin to notice an improvement in my skin, the war is declared once again and I wake up the morning with a massive breakdown of blisters and new lesions, only to start the process all over again. If my appetite begins to improve, my throat betrays me and forms a blister so that eating even ice cream can be extremely painful. I have had many hand surgeries, and all attempts to free my fingers were only temporarily successful and each one lasted for a shorter period of time. I manage quite well without fingers, but sometimes I miss the times when I could grab anything I wanted and not have to use two hands."

"When I was little, I used to sit by the window and watch the neighborhood children play during the summer from an air-conditioned living room. Kids ran in and out of sprinklers, and shadows rode by my house on bicycles. I watched and sometimes I cried because I wished I cold be out there with them, but I knew it would never happen. Every time I couldn't play, I was reminded that even in a school program for the disabled, I was different. Once I got into the upper grades, it wasn't quite as bad but I knew I never totally fit in. EB took away my childhood."

The innovative use of newly developed bio-technology and a team of dedicated investigators and clinicians are helping Dana battle a deadly form of skin cancer.

A mother, Marybeth Sheridan, of Tampa, Florida described her pregnancy as the most wonderful experience of her life however, as the Doctor pulled the baby from her womb they discovered that she had no skin on her left hand and as they touched the newly born infant, huge blisters formed all over her child before their very eyes. Marybeth recognized the fear in the doctor and nurses eyes as she was awake at the delivery but it did not compare to her terror when she realized that

they did not know what was happening to her baby. If it was not for the National EB Registry, she may not have known what was wrong with her child Samantha. Now Samantha at four years old continues to be robbed of a carefree childhood. Her parents always have to remember that one touch can severely blister or denude their child's skin. It is very hard for a four year old to understand her limitations. The burning and itching from healing and then blistering again is unbearable for their little girl.

Even though the horror of the experience for the child born with EB and its parents have not changed, today we can live with the encouraging knowledge that EB may be one of the first genetic disorders to be cured with gene therapy. It is considered the centerpiece of skin disease research and appears to be the most appropriate for gene therapy.

NIAMS funded research in EB has already produced spectacular cutting-edge science and technology. Recent progress continues to disclose distinct mutations in all three major forms of EB and these discoveries have significant implications in terms of classification, diagnosis and management for people affected with EB. Families are already benefiting from this research through clinical applications such as DNA prenatal diagnosis during the first trimester, eliminating a previously used technique that could cause further damage to an affected baby. With this new technology the obstetric team is prepared for the birth of an affected child and appropriate measures can be taken for both mother and child to minimize additional trauma. The understanding of the underlying genetic basis for EB is the basis for the development of gene therapy approaches to reverse the manifestations of EB as well as approaches to other genetic skin disorders.

Researchers have also uncovered an existing link between the molecular mechanisms leading to skin fragility in EB and the muscle wasting associated with a variant of muscular dystrophy and who knows what other associations will be uncovered through ongoing investigations? We are hopeful that new treatment for EB may come from technology that has been developed for burns and wounds whose basis comes from the knowledge and information that EB has provided in the understanding of skin biology, how the skin wounds, and why the skin does or does not heal.

DebRA of America respectfully urges Congress to continue investing in research that will indeed create the breakthroughs that will bring forth the cures for crippling and devastating diseases that are costly and deadly for millions of Americans.

On behalf of more than 100,000 Americans who suffer from EB, I again thank this Committee and Congress for the opportunity of submitting this testimony.

PREPARED STATEMENT OF HARRY C. DIETZ, M.D.

Mr. Specter and members of the Subcommittee, the members of the Coalition for Heritable Disorders of Connective Tissue (CHDCT) thank you for the opportunity to provide testimony in support of the budget of the National Institutes of Health (NIH) and the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). This is the tenth year that the CHDCT has submitted testimony and the CHDCT is grateful for the Committee's on-going support of funding for NIH research, and most particularly their support for increased funding for research on rare and genetic disorders—research which might not otherwise have been funded.

The CHDCT represents over 200 heritable disorders of connective tissue. These disorders affect several millions of the population in the United States. These heritable disorders of connective tissue are described as syndromes—genetic disorders in which the location of the mutation may have been identified, but for which there is yet no true understanding of the function of these mutations, nor an understanding of why the mutations result in such damage to the affected body systems. These are disorders for which there are no simple diagnostic tests, no effective therapies, nor any known cures. Because of the basic molecular research required to unravel the mysteries of this body of heritable connective tissue disorders, research will not only benefit those affected, but will add immeasurably to the understanding and knowledge of less complex, more prevalent disorders of connective tissue, such as osteoarthritis.

Although we tend to think of these disorders in terms of the technical names by which they are categorized for the purpose of identity and research, the individual voices of the people affected reveal the desperate quality of their lives. In a letter, a young man writes, ". . . I am being stalked by a killer. It's not some psycho lurking in the shadows, or one of the thousands of thugs loose on our streets. It's an insidious syndrome that is attacking the very building blocks that hold my body together."

In another, following the death of his daughter, a father writes, "Rachel died three months shy of her third birthday following several surgeries. Rachel's life was a inspiration to a great many people. Despite her many challenges, she always managed to have a smile for everyone she met along the way . . ."

Another woman, who lost a brother, a sister and a son: "In September of 1991 I learned about this killer. It was the first day of school for my three excited sons and the bus was just minutes from arriving. Suddenly, my son fell to the ground in convulsions and extreme pain. It took the hospital 28 hours to determine the problem—a four foot long tear in his aorta . . ."

Again, a young woman of 23 dies following a visit to the emergency room with chest pain. Her mother remembers, "Three years ago, my beautiful adult daughter died four days after being sent home from an emergency room with a misdiagnosis of stomach flu. . ."

These are the voices of those who cope daily, monthly, for a life-time, with the ignorance that still exists on how to adequately diagnose these syndromes, and the still inadequate treatment and therapies that are available. These voices compel us to look toward the NIH and to this Committee's support for increased research funding—research is our only hope. Although these disorders seem strange and unfamiliar, there are few families in the United States who have not experienced a family member, a neighbor, a friend or an acquaintance with one of these complex, multi-system disorders that have been described in the seminal textbook by Victor McKusick, Heritable Disorders of Connective Tissue. The above quotes represent only a few of the myriad of people with these disorders which have an almost infinitely varying Rosetta Stone of mutation encoding that will ultimately require deciphering in order to develop effective therapies.

The heritable connective tissue disorders represented by the voluntary health advocacy organizations which comprise the CHDCT are listed below. These are "family" disorders, since several members of a family can share the same genetic component. The names are unfamiliar and do not seem to apply to humans, yet for each of these scientific names, we can visualize thousands of affected persons, each with one's own experience.

The Chondrodysplasias have had some progress. After years, the gene has been identified for Achondroplasia—one of the most common forms of dwarfism. This condition, caused by a gene mutation early in fetal development, occurs in one of every 20,000 births. Following upon this discovery was the identification of the gene mutation for diastrophic dwarfism, a recessive form. Additional positive research is being directed toward the goal of alleviating orthopedic, neurological and respiratory/pulmonary conditions which can be lethal and have only partially effective surgical interventions.

The Ectodermal Dysplasias are a complex group of genetic disorders identified by the absent or deficient function of at least two derivatives of the ectoderm. The features of hypohidrotic ectodermal dysplasia, the most common form of the syndromes, are highly variable but generally include the inability to perspire; skin may be lightly pigmented, thin and prone to rashes or infections. Teeth may be missing or malformed; teeth which do form erupt late and may be peg-shaped or pointed. The eyes may be dry and occasionally may develop abrasions or cataracts. More than 150 syndromes have been identified with symptoms ranging from mild to severe.

Ehlers-Danlos Syndrome (EDS) is a group of genetic connective tissue disorders. There are six identified types of EDS. Unlike lupus, which is the result of antigen-antibody reactions with connective tissue, EDS is caused by a defect within the collagen itself. EDS is characterized by abnormalities of the skin, ligaments and internal organs. Symptoms include skin that is fragile, stretchable and scars easily; joints that are hypermobile, joints that dislocate, are unstable and painful with bruising and bleeding tendencies.

Epidermolysis Bullosa (EB) is a complex group of genetic disorders that disproportionately affect young children. EB causes the skin and mucus membranes of its victims to be so fragile that the slightest friction can cause blistering, shearing of skin, severe wounding and destruction of the skin and mucus membranes in both the gastrointestinal and respiratory tracts. In many cases, its symptoms resemble severe burns. EB can vary from relatively mild blistering to severe scarring, severe loss of mobility, disability and often death. Over 100,000 Americans are affected with some form of EB.

Marfan Syndrome (MFS) is a heritable disorder of the connective tissue that affects many organ systems, including the skeleton, lungs, eyes, heart and blood vessels. MFS affects both men and women of any race or ethnic group. It is estimated that at least 200,000 people in the United States have MFS or a related connective tissue disorder within this category. Although life expectancy has increased due to

open-heart surgery and improved surgical techniques, difficulty in diagnosis and the lack of effective treatments continues to have severe consequences.

Osteogenesis Imperfecta (OI) is characterized by short stature and bones that break easily, often from little or no apparent cause. Most forms of OI are the result of imperfectly formed bone collagen, the consequence of a genetic defect. A comprehensive database has been developed containing extensive information on a wide variety of clinical features of OI and many studies are underway in the hope to speed the progress toward a cure.

Pseudoxanthoma Elasticum (PXE) is an inherited disorder in which elastic fibers, which are normally found in the skin, retina of the eyes, and the cardiovascular system, become slowly calcified, producing changes in these three areas. Characteristic skin involvement usually appears on the sides of the neck and in other flexural areas, and appears as slightly thickened.

Sticklers syndrome is a common pleiotropic autosomal dominant syndrome with the following variable manifestations: early-onset myopia and retinal detachment, deafness, and cleft palate. Skeletal manifestations are sometimes called mild spondyloepiphyseal dysplasia. Physique may sometimes be described as a "marfanoid habitus," with joint hypermobility. Severely affected individuals may have mildly affected relatives.

The NIAMS-sponsored Conferences for Heritable Disorders of Connective Tissue, held in 1990 and 1995, demonstrated the value of continual review of research directions. In 1995, foremost among the suggestions were that research should focus on the development of rapid and accelerated molecular diagnosis, the evaluation of various gene therapy approaches, the development of strategies for gene delivery, and the establishment of animal models. But the greatest emphasis was placed on continuing interdisciplinary collaborations in order to prevent overlap and in order to facilitate the exchange of research. A Third Conference, to be held in the year 2000, will again serve as an opportunity to adjust the direction of research and usher in the hope and realization of future research findings.

While some of the heritable disorders of connective tissue are extremely rare, it is currently known that, as a group, they represent a major public health burden. It is important to appreciate that many common disorders involve the connective tissue and have an inherited component. For example, we now know that osteoarthritis and aortic aneurysm are bona fide members of this disease category. Aortic aneurysm is the cause of death for 2 percent of individuals in industrialized countries. The majority of individuals will have problems attributable to arthritis in their late adult life. These are but a few of many examples that underscore the importance of these disorders. The establishment of research centers allows the recruitment of geneticists, biochemists and cell biologists who will contribute their expertise to a common problem.

We, who live with heritable disorders of connective tissue, look to the establishment and support of Scientific Research Centers which will serve to coordinate research advances and enable these to be translated rapidly to advances in patient care. This is the only way to comprehensively understand the clinical burden of this disorder and to predict manifestations of disease before they occur. In the case of rare, multi-system disorders, this will be the only way to bring together enough individuals to allow for well controlled clinical trials. This goal of Scientific Research Centers for heritable disorders of the connective tissue can only be accomplished through the resources of the Institutes of the National Institutes of Health.

The CHDCT supports the AD Hoc Group for Medical Research Funding in their request to sustain the current momentum of research which will benefit all Americans. The President, the Congress, and the American people must continue the commitment that began last year to double the NIH budget by 2003. The CHDCT supports an appropriation of $18 billion for fiscal year 2000. This $2.3 billion (15 percent) increase represents the second step toward the bipartisan goal of doubling the NIH budget by fiscal year 2003. Funding biomedical research through the NIH is today's investment in America's future. The technology and the science are available to understand and ultimately cure or eradicate many of these devastating genetic disorders.

This testimony is also available on the web site of the Coalition for Heritable Disorders of Connective Tissue (CHDCT) at: www.chdct.org or a copy can be obtained by calling 516–883–8712.

PREPARED STATEMENT OF JOHN T. GRUPENHOFF, PH.D., EXECUTIVE VICE PRESIDENT, NATIONAL ASSOCIATION OF PHYSICIANS FOR THE ENVIRONMENT

Mr. Chairman and members of the Committee, a remarkable opportunity is now available to improve the environmental soundness of the biomedical research enterprise, especially in terms of energy efficiency and pollution prevention.

Background.—The Administration and Congress intend to increase funding for U.S. scientific research significantly. As for biomedical research, some congressional leaders seek to double funding for the National Institutes of Health (NIH) in the next five years; the increase for funding for the next fiscal year will be 14 percent. Total funding in those five years will be (assuming necessary increments to equal that total) $119 billion. In fiscal year 2005 the annual budget would be about $26 billion, with a continuing build-up thereafter. Funding for biomedical research portfolios in other Federal agencies will also increase. These funds will cause a major economic boom in non-profit biomedical research; it is to be expected that for-profit expenditures will increase greatly as well. Companies providing research equipment and supplies will participate in that expansion.

Enormously increased expenditures at university, college, and independent research center campuses will occur for new construction, including upgrades, and new laboratory and office equipment, all with energy use implications. There will also be a significant increase in the types and volume of wastes (solid, hazardous chemical, medical pathological, radioactive and multihazardous) which will require management and appropriate disposal.

Questions.—How can the environmental health leadership develop a program of pollution prevention and energy efficiency to prevent this enormous growth in the biomedical research enterprise from creating severe increases in pollution deleterious to human health and the environment? How can such a program have spin-off uses for other scientific research areas for which increased funding also will be available?

Support.—Considerable support to deal with these issues is likely. The White House has promulgated a number of requirements for Federal activities regarding energy efficiency, pollution prevention, and other environmental issues, and will be interested in supporting this initiative. The National Institute of Environmental Health Sciences (NIEHS), an institute of the National Institutes of Health (NIH), has indicated its strong support for a program of improving the environmental soundness of the biomedical research enterprise, both non-profit and for-profit.

The U.S. Senate fiscal year 1999 appropriations bill for the Departments of Labor-HHS-and Education included a paragraph which states:

"The Committee has learned that NIEHS is leading an effort to help make the medical research field more environmentally sound, by working with both intramural and extramural laboratories. The Committee strongly supports this activity as it recognizes that virtually every environmental or pollution problem is, or will become, a medical or public health problem."

The U.S. House of Representative's counterpart bill report stated:

"The Committee understands that NIEHS is working with its laboratories and offices to help make it more environmentally sound. The Committee commends NIEHS for its efforts and hopes that other medical and scientific research facilities will also take the necessary steps to become more environmentally sound."

Chairman John E. Porter of the House Subcommittee on Labor-HHS-Education Appropriations commented about the impacts of such increases upon environmental concerns in a videotaped statement in June, 1998:

"This will mean much greater activity and therefore an increase in the kinds of waste that can be very damaging to the environment . . . Wouldn't it be a great irony if the healthcare industry and the biomedical research community in the United States ignored environmental matters and caused the kind of pollution that can adversely affect the health of our country? Obviously, it is a tremendous responsibility of the healthcare industry and research to take environmental matters into account . . . I don't think that either healthcare workers or biomedical researchers put this at a high enough priority. They need to look at the huge effect that their activities have on our economy and on our environment."

Mr. Porter noted that the NIH has taken the lead in reducing the use of environmentally damaging products, such as chemicals, especially mixed waste and mercury, and that during the past three years the institutes have saved several million dollars through energy efficiency programs. "This is an effort that must pervade the entire research community," he said.

National Program.—A national program should be developed which has four components:

1. A national conference will be held on November 1–2, 1999 to highlight the issues, profile current "best practices," and suggest methods of implementing environmentally sound practices, including those in the entire research supply chain, which would require each link in the chain, from raw material provider to manufacturer to user, to improve environmental performance. The conference will bring together leaders from Federal agencies and national associations such as biomedical and clinical research and related organizations; university and college associations (especially involving the Association of Higher Education Facilities Officers who plan, develop, construct and run buildings and facilities at 3,600 campuses); industry manufacturers and suppliers of pharmaceuticals, chemicals, research and medical supplies; waste management companies; construction and architectural organizations; environmental organizations; voluntary health organizations; and other interested organizations to be identified.

2. Following the conference, a national education and training program to promote environmental soundness, including energy efficiency and pollution prevention, at campuses and facilities which receive biomedical research grants, combining the efforts of the researchers and the facility managers, should be developed.

3. A research agenda should be developed both for the improvement in the use and disposal of biomedical research materials and for building design and construction of research facilities, including energy efficiency and development of standards for healthy building design.

4. A clearinghouse should be created to inform the field of "best practices" available for widespread, including international, use (a "virtual clearinghouse" on the Internet would be the most useful form). Energy efficiency and pollution prevention should be stressed.

Timing.—Two spin-off activities are likely; many more will become evident during the above-proposed activities. First, as organizations work on these issues, it will become apparent that continuing collaborative efforts are needed not only to improve environmental soundness in basic and clinical biomedical research, but in the healthcare enterprise generally, and an organizational structure should be developed to pursue them—perhaps a "Council of Health and Medical Research Professionals for the Environment," composed of a wide spectrum of healthcare and research organizations, could be created.

Second, throughout the process there will be the potential to determine "best practices," and to apply lessons learned and products developed to the nonbiomedical scientific enterprise, which will also experience rapid growth. A campus-based education program as described above should be adapted to deal with this opportunity.

There will be many benefits of such an effort, including improved energy efficiency that will save money for additional research, use and disposal of alternative chemicals and other research materials that can protect workers and probably save money, and improved healthy workplaces for researchers.

One additional benefit is that research teams, by participating in such an effort, will be taking responsibility for the protection of the environment as an integral part of the research, disease prevention and healing mission of biomedical research. If such actions are properly promulgated to the community where the research is done, the public will be assured that its environment is being protected and will look favorably on the researchers, on the research being done, and on the campus where it takes place.

We therefore propose that bill report language come from this committee in support of these efforts and NAPE will be pleased to work with your staff to develop such language.

Thank you for all you have done, in funding biomedical research, to improve the health of people worldwide.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

We appreciate the opportunity to provide testimony to the Labor, Health and Human Services, and Education Subcommittee on two funding items of great importance to the Humane Society of the United States (HSUS) and its 6.7 million members and constituents. As the largest animal protection organization in the country, the HSUS urges the Committee to address these priority issues in the fiscal year 2000 budget.

CLASS B RANDOM SOURCE ANIMAL DEALERS

The HSUS urges the Committee to include report language directing NIH to extend its policy prohibiting the use of animals obtained from Class B dealers for intramural research, to the extramural research funded by NIH as well. Class B deal-

ers acquire the animals they sell to biomedical research facilities from a variety of sources including "free to good home" ads, puppy mills, animal shelters, and outright theft of family pets. Additionally, squalid conditions, abusive handling, sickly and under cared for animals, and sloppy record-keeping are the hallmarks of Class B dealers. As Robert A. Whitney, D.V.M. and former Director of both the National Center for Research Resources and the Office of Animal Care and Use at NIH, testified in July 1997, "The continued existence of these virtually unregulatable Class B dealers erodes the public confidence in our commitment to appropriate procurement, care, and use of animals in the important research to better the health of both humans and animals."

Just six weeks ago, nine individuals were convicted of charges related to the theft of pets for sale to research laboratories. The leader of the group was a USDA licensed Class B dealer who has sold hundreds of dogs to research facilities including the University of Southern California, Cedars Sinai Medical Center, and the Seattle Institute of Biomedical and Clinical Research, which collectively received over $114,000,000 in funding from NIH in fiscal year 1998. Taxpayers funds should not be used to purchase stolen animals.

We commend NIH for its policy prohibiting the use of animals obtained from Class B dealers in intramural research. NIH should exercise the same caution and concern with respect to its grant recipients. Extending this sound policy to the extramural research program will assure the public that animals purchased with government funds have not been stolen from their families.

CHIMPANZEE SANCTUARY

Laboratories in the United States currently support hundreds of chimpanzees no longer needed for experimental medical research purposes. Establishing permanent sanctuaries is the most cost-effective and humane solution to this problem, and one which requires a public/private partnership. The HSUS is pleased to join forces on this request with a broad coalition of experts in the care and management of captive and wild chimpanzees, including research, animal protection, zoo, and sanctuary representatives (please see list below).

Sufficient similarities exist between chimpanzees and human beings that the chimpanzee has served as a human surrogate in research in the United States since the mid 1950s. Since then, chimpanzees have been bred extensively for use in many types of research, including space research, the development of infectious disease vaccines, biomedical/biobehavioral studies, and cognitive research. In the mid 1980s, an initial investigation indicated that chimpanzees might serve as a vehicle to understand the human immunodeficiency virus (HIV). A breeding program was established to assure sufficient numbers of chimpanzees to meet the research requirements. It has become clear, ten years later, that there are large numbers of unneeded chimpanzees in laboratories due to the success of the chimpanzee breeding program, a decreased need in biomedical research, the ethical considerations posed by such research, and the high cost of maintenance. Currently, there are estimated to be several hundred chimpanzees no longer needed in biomedical research and the numbers are anticipated to grow.

In response to the perceived oversupply of chimpanzees in laboratories and anticipating a need for a new management plan, the National Research Council was asked in 1994 to address these issues:

—The size of the breeding colony required to support future research needs
—Issues of ownership, long-term care, and use in research
—Mechanisms by which non-governmental organizations could assist in achieving appropriate goals and solutions for the long-term care of chimpanzees

Among the recommendations of the NRC's 1997 report, "Chimpanzees in Research —Strategies for Their Ethical Care, Management, and Use," were:

—A five year breeding moratorium (1997–2001) should be adopted
—Euthanasia should not be considered as a management option
—Sanctuaries should be established

Housing and maintaining chimpanzees in laboratories is a costly process, and poses management problems, including significant challenges in providing captive-bred chimpanzees with appropriate living conditions. Currently, NIH is supporting more than 600 chimpanzees at a cost of between $15 and $30 per day per individual. These chimpanzees can be maintained in better environments at a far lower cost in a sanctuary setting, where they would be allowed to live the remainder of their natural lives without further invasive research or return to a laboratory. Sanctuaries designed and maintained by experts in the care and management of this species are the appropriate solution to the problem of lifetime care for unneeded chimpanzees, as recommended in the NRC report and by other experts.

We urge the Committee to provide $12.5 million in fiscal year 2000 to construct a model sanctuary facility that can begin to address the serious problem of unneeded chimpanzees currently housed in laboratories. We respectfully recommend that these funds be allocated as follows: $9.5 million for the initial construction of a sanctuary facility for 300 chimpanzees; $1.5 million for operating expenses in the first year (e.g. to purchase start-up equipment and supplies, and hire initial staff); $1 million to provide interim support for chimpanzees awaiting retirement; and $450,000 for administration and oversight of this program by the NIH. For fiscal year 2001 and years thereafter, we also suggest funding of at least $1.5 million for operating costs and $450,000 for administration of this program by NIH, plus whatever new funds will be required to take care of additional chimpanzees that are found to be surplus to NIH's requirements.

The HSUS appreciates the Committee's attention to this pressing concern, and is pleased to submit this request for funding of a model chimpanzee sanctuary on behalf of HSUS President and CEO, Paul Irwin, HSUS Senior Vice President for Research, Education and International Issues, Dr. Andrew Rowan, and the following 44 coalition members:

Dr. Kate Baker, Research Associate.—Yerkes Regional Primate Research Center, Emory University (Atlanta, GA)

Alan Berger, Executive Director.—Animal Protection Institute (Sacramento, CA)

Dr. Tammie Bettinger, Coordinator of Scientific Studies.—Cleveland Metroparks Zoo (Cleveland, OH)

Dr. Mollie Bloomsmith, Director of Research and Director of TECHlab.—Zoo Atlanta (Atlanta, GA); Affiliate Scientist.—Yerkes Regional Primate Research Center, Emory University (Atlanta, GA)

Dr. Sarah Boysen, Director of Primate Cognition Project and Associate Professor of Comparative Psychology.—Ohio State University (Columbus, OH)

Dr. Linda Brent, President.—Chimp Haven, Inc. (San Antonio, TX)

Dr. Thomas Butler, Chairman, Department of Laboratory Animal Medicine.—Southwest Foundation for Biomedical Research (San Antonio, TX); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use

Cindy Carroccio, Director.—Austin Zoo (Austin, TX)

Peggy Cunniff, Executive Director.—National Anti-Vivisection Society (Chicago, IL headquarters)

Dr. Philip Davies, Executive Director, Immunology & Rheumatology.—Merck & Co., Inc. (Rahway, NJ); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use

Dr. Frans de Waal, Chandler Professor of Primate Behavior, Psychology Department, and Director of LIVING LINKS CENTER.—Yerkes Regional Primate Research Center, Emory University (Atlanta, GA)

Adele Douglass, Director.—American Humane Association (D.C. headquarters)

Dr. Stephen Easley, Director.—Easley and Associates, Professional Consultants (Alamorgordo, NM)

Jo Fritz, Director.—Primate Foundation of Arizona (Mesa, AZ); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use

Dr. Randy Fulk, Curator of Research and Species Coordinator for the Chimpanzee Species Survival Plan.—North Carolina Zoo (Asheboro, NC)

Dr. William Hopkins, Professor of Psychology.—Berry College (Rome, GA); Research Associate—Yerkes Regional Primate Research Center, Emory University (Atlanta, GA)

Dr. Thomas Insel, Director.—Yerkes Regional Primate Research Center, Emory University (Atlanta, GA)

Dr. Michael Kastello, Executive Director, Research Resources.—Merck & Co., Inc. (Rahway, NJ)

Dr. Michale Keeling, Professor and Chairman, Department of Veterinary Sciences.—University of Texas M.D. Anderson Cancer Center (Bastrop, TX)

Dr. James King, Professor of Psychology—University of Arizona (Tucson, AZ)

Linda Koebner, Executive Director.—Chimp Haven, Inc. (New York City, NY)

Dr. Virginia Landau, Staff Primatologist.—Jane Goodall Institute (Silver Spring, MD); Director—Chimpan Zoo (Tucson, AZ)

Debbie Leahy, President.—Illinois Animal Action (Warrenville, IL)

Dr. Terry Maple, President.—American Zoo and Aquarium Association (Silver Spring, MD); President and CEO—Zoo Atlanta (Atlanta, GA)

Dr. Linda Marchant, Professor of Anthropology.—Miami University (Oxford, OH)

Dr. Michele Martino, Assistant Veterinarian.—Southwest Foundation for Biomedical Research (San Antonio, TX)

Dr. Preston Marx, Senior Scientist.—Aaron Diamond AIDS Research Center (New York City, NY headquarters); Professor of Tropical Medicine—Tulane Regional Primate Research Center; and Tulane School of Public Health and Tropical Medicine (Covington, LA)

Dr. William McGrew, Professor of Zoology.—Miami University (Oxford, OH)

Dr. Robert Mitchell, Associate Professor of Psychology.—Eastern Kentucky University (Richmond, KY)

Tina Nelson, Executive Director.—American Anti-Vivisection Society (Jenkinstown, PA) Barbara Newell, Esq.—Animal Legal Defense Fund; Great Ape Legal Project (Rockville, MD)

Dr. F. Barbara Orlans, Senior Research Fellow.—Kennedy Institute of Ethics, Georgetown University (Washington, D.C.)

Ingrid Porton, Mammal Curator/Primates.—Saint Louis Zoological Park (St. Louis, MO)

Patti Ragan, Director.—Center for Orangutan & Chimpanzee Conservation (Wauchula, FL)

Dr. Thomas Jefferson Rowell, Director.—University of Southwestern Louisiana, New Iberia Research Center (New Iberia, LA)

Dr. Duane Rumbaugh, Director.—Language Research Center, Georgia State University (Atlanta, GA)

Dr. Peter Theran, Vice President of Health and Hospitals Division.—Massachusetts Society for the Prevention of Cruelty to Animals (Boston, MA); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use

Dr. Erna Toback.—Scientific Advisory Board of Chimp Haven, Inc. (Los Angeles, CA); American Society of Primatologists; University of Stirling (Stirling, Scotland)

April Truitt, President.—Primate Rescue Center, Inc. (Nicholasville, KY)

Dr. Paul Waldau, Vice President.—Great Ape Project International (Boston, MA)

Lisa Weisberg, Esq., Vice President, Government Affairs.—American Society for the Prevention of Cruelty to Animals (New York City, NY)

Steven Wise, Esq., President.—Center for the Expansion of Fundamental Rights, Inc. (Needham, MA)

Dr. Thomas Wolfle, Retired Director.—Institute of Laboratory Animal Research, National Research Council; Program Director, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use

Dr. Richard Wrangham, Professor of Anthropology.—Harvard University (Cambridge, MA)

Again, we appreciate the opportunity to share our views and priorities for the Labor, Health and Human Services, and Education Appropriation Act of fiscal year 2000. We hope the Committee will be able to accommodate these modest requests to address some very pressing problems affecting animals across the United States. Thank you for your consideration.

LETTER FROM DR. KATE BAKER, ET AL.

APRIL 15, 1999.

Hon. ARLEN SPECTER, *Chairman,*
Labor, Health and Human Services, and Education Subcommittee, Senate Committee on Appropriations, Washington, DC.

DEAR MR. CHAIRMAN: As experts in the care and management of captive and wild chimpanzees, we are very concerned that laboratories in the United States currently support hundreds of unneeded or likely to be "surplus" chimpanzees in need of retirement and sanctuary. The 46 names listed below represent a broad coalition including research, animal protection, zoo, and sanctuary representatives. We urge the Committee's support for funding to establish permanent sanctuaries, as the most cost-effective and humane solution to the problem of unneeded chimpanzees and one which requires a public/private partnership.

BACKGROUND

Sufficient similarities exist between chimpanzees and human beings that the chimpanzee has served as a human surrogate in research in the United States since the mid 1950s. Since then, chimpanzees have been bred extensively for use in many

types of research, including space research, the development of infectious disease vaccines, biomedical/biobehavioral studies, and cognitive research.

In the mid 1980s, an initial investigation indicated that chimpanzees might serve as a vehicle to understand the human immunodeficiency virus (HIV). A breeding program was established to assure sufficient numbers of chimpanzees to meet the research requirements. It has become clear, ten years later, that there are large numbers of unneeded chimpanzees in laboratories due to the success of the chimpanzee breeding program, the decreased need in biomedical research, the ethical considerations posed by such research, and the high cost of maintenance. Currently, there are estimated to be several hundred chimpanzees no longer needed in biomedical research and the numbers are anticipated to grow.

In response to a perceived oversupply of chimpanzees in laboratories and anticipating a need for a new management plan, the National Research Council was asked in 1994 to address the following issues:

—The size of the breeding colony required to support future research needs
—Issues of ownership, long-term care, and use in research
—Mechanisms by which non-governmental organizations could assist in achieving appropriate goals and solutions for the long-term care of chimpanzees

Among the recommendations of the NRC's 1997 report, "Chimpanzees in Research—Strategies for Their Ethical Care, Management, and Use," were:

—A five year breeding moratorium (1997–2001) should be adopted
—Euthanasia should not be considered as a management option
—Sanctuaries should be established

Housing and maintaining chimpanzees in laboratories is a costly process, and poses management problems, including significant challenges in providing captive-bred chimpanzees with appropriate living conditions. Currently, NIH is supporting approximately 600 chimpanzees at a cost of between $15 and $30 per day per individual. These chimpanzees can be maintained in better environments at a far lower cost in a sanctuary setting, where they would be allowed to live the remainder of their natural lives without further invasive research or return to a laboratory. Sanctuaries designed and maintained by experts in the care and management of this species are the appropriate solution to the problem of lifetime care for unneeded chimpanzees, as recommended in the NRC report and by other experts.

REQUEST FOR FUNDING

For fiscal year 2000, we are requesting $12.5 million to construct a model sanctuary facility that can begin to address the serious problem of unneeded chimpanzees currently housed in laboratories. We respectfully recommend that these funds be allocated as follows: $9.5 million for the initial construction of a sanctuary facility for 300 chimpanzees; $1.5 million for operating expenses in the first year (e.g. to purchase start-up equipment and supplies, and hire initial staff); $1 million to provide interim support for chimpanzees awaiting retirement; and $450,000 for administration and oversight of this program by the NIH. For fiscal year 2001 and years thereafter, we also suggest funding of at least $1.5 million for operating costs and $450,000 for administration of this program by NIH, plus whatever new funds will be required to take care of additional chimpanzees that are found to be surplus to NIH's requirements.

We very much appreciate your attention and look forward to working closely with you to obtain funds for this urgently-needed initiative.

Sincerely,

DR. KATE BAKER, *Research Associate, Yerkes Regional Primate Research Center, Emory University (Atlanta, GA).*

ALAN BERGER, *Executive Director, Animal Protection Institute (Sacramento, CA).*

DR. TAMMIE BETTINGER, *Coordinator of Scientific Studies, Cleveland Metroparks Zoo (Cleveland, OH).*

DR. MOLLIE BLOOMSMITH, *Director of Research and Director of TECHlab Zoo, Atlanta (Atlanta, GA); Affiliate Scientist Yerkes Regional Primate Research Center, Emory University (Atlanta, GA).*

DR. SARAH BOYSEN, *Director of Primate Cognition Project and Associate Professor of Comparative Psychology, Ohio State University (Columbus, OH).*

DR. LINDA BRENT, *President, Chimp Haven, Inc. (San Antonio, TX).*

DR. THOMAS BUTLER, *Chairman, Department of Laboratory Animal Medicine Southwest Foundation for Biomedical Research (San Antonio, TX); Member, National Research Council Committee that produced 1997*

Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.

CINDY CARROCCIO, *Director, Austin Zoo (Austin, TX).*

PEGGY CUNNIFF, *Executive Director, National Anti-Vivisection Society (Chicago, IL headquarters).*

DR. PHILIP DAVIES, *Executive Director, Immunology & Rheumatology Merck & Co., Inc. (Rahway, NJ); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.*

DR. FRANS DE WAAL, *Chandler Professor of Primate Behavior, Psychology Department, and Director of LIVING LINKS CENTER Yerkes Regional Primate Research Center, Emory University (Atlanta, GA).*

ADELE DOUGLASS, *Director, American Humane Association (D.C. headquarters).*

DR. STEPHEN EASLEY, *Director, Easley and Associates, Professional Consultants (Alamorgordo, NM).*

Jo Fritz, *Director, Primate Foundation of Arizona (Mesa, AZ); Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.*

DR. RANDY FULK, *Curator of Research and Species Coordinator for the Chimpanzee Species Survival Plan, North Carolina Zoo (Asheboro, NC).*

DR. WILLIAM HOPKINS, *Professor of Psychology, Berry College (Rome, GA); Research Associate Yerkes Regional Primate Research Center, Emory University (Atlanta, GA).*

DR. THOMAS INSEL, *Director, Yerkes Regional Primate Research Center, Emory University (Atlanta, GA).*

PAUL IRWIN, *President and CEO, The Humane Society of the United States (Washington, D.C.).*

DR. MICHAEL KASTELLO, *Executive Director, Research Resources Merck & Co., Inc. (Rahway, NJ).*

DR. MICHALE KEELING, *Professor and Chairman, Department of Veterinary Sciences, University of Texas, M.D. Anderson Cancer Center (Bastrop, TX).*

DR. JAMES KING, *Professor of Psychology University of Arizona (Tucson, AZ).*

LINDA KOEBNER, *Executive Director, Chimp Haven, Inc. (New York City, NY).*

DR. VIRGINIA LANDAU, *Staff Primatologist, Jane Goodall Institute (Silver Spring, MD); Director, Chimpan Zoo (Tucson, AZ).*

DEBBIE LEAHY, *President, Illinois Animal Action (Warrenville, IL).*

DR. TERRY MAPLE, *President, American Zoo and Aquarium Association (Silver Spring, MD); President and CEO, Zoo Atlanta (Atlanta, GA).*

DR. LINDA MARCHANT, *Professor of Anthropology, Miami University (Oxford, OH).*

DR. MICHELE MARTINO, *Assistant Veterinarian, Southwest Foundation for Biomedical Research (San Antonio, TX).*

DR. PRESTON MARX, *Senior Scientist, Aaron Diamond AIDS Research Center (New York City, NY headquarters); Professor of Tropical Medicine, Tulane Regional Primate Research Center; and Tulane School of Public Health and Tropical Medicine (Covington, LA).*

DR. WILLIAM MCGREW, *Professor of Zoology, Miami University (Oxford, OH).*

DR. ROBERT MITCHELL, *Associate Professor of Psychology, Eastern Kentucky University (Richmond, KY).*

TINA NELSON, *Executive Director, American Anti-Vivisection Society (Jenkinstown, PA).*

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PATTI RAGAN, *Director, Center for Orangutan & Chimpanzee Conservation (Wauchula, FL).*

DR. ANDREW ROWAN, *Senior Vice President for Research, Education, and International Issues, The Humane Society of the United States (Washington, D.C.).*

DR. THOMAS JEFFERSON ROWELL, *Director, University of Southwestern Louisiana, New Iberia Research Center (New Iberia, LA).*

DR. DUANE RUMBAUGH, *Director, Language Research Center, Georgia State University (Atlanta, GA).*

DR. PETER THERAN, *Vice President of Health and Hospitals Division, Massachusetts Society for the Prevention of Cruelty to Animals (Boston, MA); and Member, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.*

DR. ERNA TOBACK, *Scientific Advisory Board of Chimp Haven, Inc. (Los Angeles, CA); American Society of Primatologists; University of Stirling (Stirling, Scotland).*

APRIL TRUITT, *President, Primate Rescue Center, Inc. (Nicholasville, KY).*

DR. PAUL WALDAU, *Vice President, Great Ape Project International (Boston, MA).*

LISA WEISBERG, ESQ., *Vice President, Government Affairs American Society for the Prevention of Cruelty to Animals (New York City, NY).*

STEVEN WISE, ESQ., *President, Center for the Expansion of Fundamental Rights, Inc. (Needham, MA).*

DR. THOMAS WOLFLE, *Retired Director, Institute of Laboratory Animal Research, National Research Council; Program Director, National Research Council Committee that produced 1997 Report, Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.*

DR. RICHARD WRANGHAM, *Professor of Anthropology Harvard University (Cambridge, MA).*

PREPARED JOINT STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND THE ASSOCIATION OF POPULATION CENTERS

Thank you, Mr. Chairman for this opportunity to present the position of the Population Association of America (PAA) and the Association of Population Centers (APC) to the Subcommittee on Labor, Health and Human Services and Education on fiscal year 2000 funding for the National Institutes of Health (NIH), specifically the National Institute on Aging (NIA), and the National Institute of Child and Maternal Health (NICHD). You are a long-standing friend of both organizations and we want to emphasize how grateful we are for your appreciation and support of demographic research.

As you know, PAA is a scientific and educational society of professionals working in demographic research. APC is a consortium of 27 leading American population research centers. In addition to their academic roles, members of both organizations provide federal, state and local government agencies, as well as private sector institutions, with data and research to guide decision-making.

In this testimony, we wish to express our support for the National Institutes of Health (NIH), specifically NIH support for demographic, social and behavioral research, and share recent demographic trends and research findings of interest with Congress.

Demographic research covers many issues important to our nation, such as retirement, minority health, disability and long term care, child care, immigration, labor force participation, worker retraining, family formation and dissolution, and population forecasting. The United States is undergoing far-reaching shifts in its demographic composition and distribution. Such changes often are not recognized or understood until they confront society with new and immediate needs—often requiring federal and state expenditures. Incorporating demographic, social and behavioral research into long term policy discussions allow such changes to be tracked and anticipated in a manner that promotes more coherent and efficient planning and policy implementation.

NIH, specifically the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA) provide primary support for demographic research. We would like to take this opportunity to share with you information concerning aging, trends in adolescent health, the effects of welfare reform on children and families, profiles of legal immigrants, and changes in fatherhood.

THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

NICHD has a well-established, successful population research program. NICHD is currently funded at $750.9 million with $44.1 million of the budget for research funded through the Demographic and Behavioral Sciences. Among the many areas of demographic research supported by NICHD are families and household composition; marriage and family change; fertility and family planning; teen pregnancy; mortality; HIV prevention; and population movement, distribution and composition. NICHD also funds a highly regarded population research centers program. Population research centers provide a critical core of professionals who conduct research in a cost-effective manner. Further, the centers' training programs are an essential source of population scientists who bring fresh perspectives, ideas and improved methodologies to demographic research.

As you can see from the wide range of research topics listed above, NICHD-supported demographic research provides important, ongoing information critical to policymakers. We are pleased to provide information in this testimony that focuses on Add Health, the Fatherhood Initiative, the effects of welfare reform on children and families, profiles of legal immigrants, and the Family and Child Well-Being Research Network.

National longitudinal study of adolescent health (add health)

The Add Health survey is the first comprehensive national study of the social, psychological and environmental determinants of adolescent health. This study provides information that is valuable to parents, educators, researchers and policymakers. Although teens are generally a very healthy sub-group in the population, one in five has a serious health problem, which are often costly and affect adult health.

In the Add Health Study, the collection of global network data on friendships has provided a means to study the influence of peers on adolescent behavior. Early results have documented that peers can have as great or greater influence than parents in some arenas.

In fiscal year 1999 NICHD funded a follow up to the Add Health study. In 2000 the 20,000 adolescents first interviewed in 1995 will be re-interviewed to explore how the behaviors and conditions present in adolescence can help to predict health status in adulthood.

Determining how to prevent adolescent health problems will contribute to a stronger and healthier society. PAA and APC hope this committee will continue to support research, such as the Add Health study, that adds to our understanding of changes in the teenage and adult population.

Fatherhood

The decline of the incidence of marriage weakens the ties of men to women and children, with a resulting burden to the welfare system and to women and children themselves. Thus, it is important to understand the conditions which help to sustain men's participation in their family's lives. NICHD, in conjunction with the Federal interagency Forum on Child and Family Statistics and the National Center on Fathers and Families, launched a Fatherhood Initiative to review the capacity of the federal statistical system to conceptualize, measure and gather information from men about how they became fathers and how they provide economic and emotional support to their children.

Among the results of this effort are the inclusion of men in the National Survey of Family Growth and the development of a fathers component in the Early Childhood Longitudinal Survey and the inclusion of basic research on fathers in the Early Head Start Research and Evaluation Project. NICHD is also supporting research to understand factors leading to stable unions among unmarried fathers and mothers.

The roles fathers play in the lives of their children are strongly affected by the father's relationship to the mother: the access of fathers to their children is highest when parents are living together. In cases of divorce, a NICHD grantee has shown that many fathers have enormous desire to maintain contact with their children, and with intervention can continue to be major influences in the lives of their children even after the divorce.

Welfare reform effects on children and families

The 1996 welfare reform act and the subsequent changes in the welfare programs of nearly every state constitute the greatest shift in social policy for low-income families with children since the Social Security Act of 1935. Since the passage of welfare reform legislation, welfare caseloads have dropped 40 percent. Yet we know very little about how these changes will affect these children and families. Both positive and negative scenarios can be constructed.

The positive scenario is that leaving welfare for a job will make a mother feel more self-sufficient, raise her self-esteem, bolster her parenting behavior and provide a better role model for her children to emulate. Critics point to the challenges of combining employment and parenting for single parents with few economic resources. Jobs are difficult to find, low paying, and often do not provide health insurance. Good and affordable child-care may be difficult to obtain. The risk for children is increased parental distress, poorer parenting, inadequate childcare and greater economic hardship.

We simply do not know which scenario will prove most accurate over time. NICHD is supporting several projects to study the effects of welfare reform on children and families. The NICHD supported studies in cities such as San Antonio, Boston, Chicago, Milwaukee and Los Angeles should provide us with a clearer understanding of the ways that children and their families are affected by this momentous change in social policy. These in depth community based studies will examine the impact of support from family, community networks, and public programs in helping families make the transition to self sufficiency while assessing the impact on child health and development.

Research on immigration

Immigration has always played an important part in shaping the face and future of the United States. Understanding the trends in immigration and the characteristics of immigrants is vital for making informed policy decisions. NICHD, the Immigration and Naturalization Service (INS), the National Science Foundation (NSF), and the National Institute on Aging (NIA) have cooperatively funded a New Immigrant Survey Pilot Study (NIP). This study will provide immediate policy relevant information on immigrants in the United States and also serve as the foundation for long term research on immigrants.

Much of the conventional wisdom on immigrants has been repudiated in recent NICHD supported studies. For example, legal immigrants are better schooled, on average, than the native born; the proportion with postgraduate education is almost three times larger than among the native born, at the same time, there is also a substantial group without a high school education. Overall, however, the quality of legal immigrants entering the United States is improving. Influenced by changes in immigration laws and changing economic conditions, the skill composition of immigrants to the United States has risen.

Family and child well-being research network

Finally, we wanted to bring you up-to-date on NICHD's Family and Child Well-Being Research Network—an interdisciplinary data system focusing on child- and family-related research that relies on cross-agency cooperation. This year the network has been renewed and expanded. The new network is comprised of scientists from nine universities collaboratively working with federal officials from NICHD, the Office of the Assistant Secretary for Health, of the Department of Health and Human Services (HHS), the Administration of Children and Families of HHS, the Census Bureau and the Department of Education. This network currently addresses a variety of questions about the interrelations between parent characteristics, family structure and organization, neighborhood attributes and different forms of social support. The network is committed to increasing the visibility of basic research findings to those involved in formulating public policy. Projects such as the Family and Child Well-Being Research Network perform the important task of helping synthesize research into sensible policy solutions.

The Network, in cooperation with federal statistical agencies and the research community developed a comprehensive set of indicators of child well-being. Information from these indices is published annually by executive order. The first report titled, America's Children: Key National Indicators of Well-Being, was released in 1997 and is now published on an annual basis. This report provides a much improved information base that summarizes the changes in the overall well being of American children and families on an annual basis.

PAA and APC enthusiastically support initiatives such as NICHD's Family and Child Well-Being Research Network that provide quick access to data and are effi-

cient and effective resources for time sensitive policy-related research in cross-disciplinary fields.

THE NATIONAL INSTITUTE ON AGING (NIA)

The NIA also has a well established and widely respected demographic research program, which provides crucial information on the implications of an aging of the American Population for our country. Currently, the NIA is funded at $596.5 million, with $39.6 million of that budget dedicated to demographic research—training, career development, and demographic, economic and epidemiological research. As the U.S. population ages and Congress contemplates sweeping changes in Medicare and Social Security, the demography of the elderly steadily becomes more important. The NIA has a strong history of supporting the collection of data, which allows demographers to study questions of concern to policymakers. Chief among these is the NIA-supported studies, the Health and Retirement Study (HRS) and its auxiliary survey, the Asset and Health Dynamics of the Oldest-Old (AHEAD) study. You have been a solid supporter of these two studies over the years, Mr. Chairman, and we would like to express our gratitude for your support.

Health and retirement study (HRS)

As you know, the HRS focuses on mid-life work and health dynamics and collects biennial data on health and disability, work, health insurance, pensions and retirement plans, and obligations to family that may bear on retirement decisions. Using HRS data, researchers are able to explore issues related to health, disability and labor force participation; prospects for economic security; cognitive changes, health insurance coverage in the decade before Medicare eligibility.

Researchers have long known that persons with higher levels of wealth and income have better health and live longer. The reasons for this relationship are not well understood. Is it that income and wealth cause better health through better access to health care or access to better health care? Or is it that poor health causes lower levels of wealth and income by decreasing work, reducing earnings, and increasing health care expenditures? HRS panel data are shedding some light on these difficult questions. An economist from RAND has recently shown, for example, that out-of-pocket health expenses account for only a small share of the reductions in wealth after an adverse health event. Furthermore, those without health insurance have just as large a decline in wealth as those with health insurance. Subsequent to a major health event, middle-aged persons tend to reduce their work hours or retire completely and use their accumulated savings in place of earnings. These results have important implications for spend-down to Medicaid eligibility and old-age poverty, especially for older women who tend to outlive their spouses.

Education also is linked to health as well as wealth and income. Analyses of HRS by researchers at the University of Michigan suggest that education appears to have an enduring effect on health decisions. Among respondents who suffered a heart attack between the first two waves of the HRS, 90 percent of college grads quit smoking compared with only 10 percent of those with less than High School education. Related HRS research also shows that, among middle-aged diabetics, education raises their health investment in managing their disease through diet.

Asset and health dynamics of the oldest-old (AHEAD)

The companion survey of HRS, AHEAD, provides unique information on the dynamics of health, economic resources and health care services. The study provides badly needed data on the costs and burdens of chronic disease and the consequences for the extended family. Over time, AHEAD will provide data on how families redistribute their resources across generations, and how these flows interact with public sector transfers. AHEAD informs policy decisions on initiatives such as Medicare/Medicaid coverage for community long-term care and prescription drug benefits.

In addition to economic factors, sustained activity, such as PT work and volunteering, are thought to affect the well-being and health of the very old. AHEAD data indicate that there is a beneficial effect of volunteer work on cognition, health and survivorship. Volunteer work also is associated with higher education and wealth suggesting that social activities may be yet another pathway by which socio-economic status affects health, even in advanced old age.

AHEAD data also collaborate improvements in old age health, first described by Duke University researchers using data from another NIA-supported project, the National Long-term Care Survey. Across the first two waves of AHEAD (1993–95), respondents have shown very little overall decline in basic cognitive functioning. Higher education is protective of cognitive ability in old age.

Finally, PAA and APC are interested in and support the current efforts to strengthen the Federal Forum on Aging Related Statistics that coordinates data

across federal agencies. The forum is an example of NIA's interest in supporting NIH's innovative endeavor of streamlining federal databases and making data accessible to researchers from varied fields.

PAA and APC would like to thank you for the opportunity to present this information. Demographic data and research are important tools for policymakers that can both save public funds and promote more informed decisionmaking. If this vital research is to continue producing relevant and timely information, adequate funding and congressional support are needed. The Population Association of America and the Association Population Centers support an increase in the range of 15 percent to sustain the momentum of demographic research in the National Institutes of Health as part of the broadly based support to double the funding for the NIH over the next 5 years.

PREPARED STATEMENT OF PATRICIA KNAUB, DEAN, COLLEGE OF HUMAN ENVIRONMENTAL SCIENCES, OKLAHOMA STATE UNIVERSITY

Mr. Chairman and Members of the Committee: My name is Patricia Knaub. I am Dean of the College of Human Environmental Sciences at Oklahoma State University. This testimony is in behalf of the Board of Human Sciences of the National Association of State Universities and Land Grant Colleges (NASULGC). The Board on Human Sciences (BOHS) represents those State Universities and Land Grant Colleges which conduct research, extension and education programs on nutrition and health, food safety and product development, human development from infancy to old age, family and community viability, and workforce development. Our work is supported by federal, state, and privately funded grants as well as CSREES formula funds and USDA competitive grants programs. In 1998 member colleges reported over $32 million in projects supported by HHS funding, more than $7 million of which was from various National Institutes of Health, approximately $3 million supporting ACF projects, $25,000 from CDC, and others from block grants to the various states.

The BOHS strongly supports the proposed fiscal year 2000 Health and Human Services budget with special emphasis on those programs for which our colleges are prepared to carry out the work. As constituent units of major state and Land Grant Universities, human sciences colleges are linked through a network which fosters regional and national collaboration on research and education programs. Located within comprehensive universities human sciences faculty collaborate with faculties in chemistry, biochemistry, biology, social sciences, agriculture, and in a number of cases where colocated, with schools of medicine or veterinary medicine. With responsibility for research, academic and outreach programs, human sciences faculty are able to address problems from discovery to dissemination, by engaging students in the process, and by translating information through extension to the public. For example, discovery of nutrient metabolic precesses in our laboratories is translated into dietary guidelines used by industries, medicine, and for public educational programs. Human Sciences faculty research on brain development in children can be translated into guidance for the medical professions as well as for teachers of child development and parent education.

NATIONAL INSTITUTES OF HEALTH (NIH)

The fiscal year 2000 requests $15.9 billion for NIH, a $320 million or 2.1 percent increase over fiscal year 1999. The BOHS strongly endorses the four programmatic themes addressed in this budget:

(1) exploiting genomics, expanding work on animal model systems, and learning to gather and use complex biological systems information;

(2) reinvigorating clinical research by recruiting, training and retaining clinical investigators, supporting clinical trials, networks, and databases, and developing partnerships with managed care, foundations, industries and other federal agencies;

(3) harnessing the expertise of allied disciplines such as chemistry, engineering, computer science, and physics in order to form interdisciplinary teams to design new foods, drugs, biomaterials, imaging molecules, chromosomes, cells, and organs; and

(4)reducing health disparities at home and abroad through research, education, testing interventions and building international research capacity.

By virtue of a systems approach to human problem solving, human sciences faculty are prepared to participate in the problem solving outlined by these themes and to translate findings into academic instruction and information useful to an array of professions, industries, and the general public through research and cooperative extension.

The BOHS also supports the inclusion in the NIH request of $512 million for individual and institutional training to support nearly 15,700 pre- and post-doctoral research trainees.

ADMINISTRATION FOR CHILDREN AND FAMILIES (ACF)

One of the five fiscal year 2000 legislative and program priorities of the BOHS is improving child care and education through daycare and the home setting. The ACF fiscal year 2000 budget requests $38 billion, of which $9.4 billion supports discretionary programs, $28.6 billion is entitlement budget authority. The programs include Head Start, reduction of family violence, child care, child support, foster care and adoption, and Temporary Assistance for Needy Families (TANF). Human sciences faculties in our member institutions support passage of child care legislation with an emphasis on quality of care. Quality can be assured through research based education of early childhood teachers and administrators, appropriate licensing and policy guidelines, and collaboration with local industries, government and parents.

The fiscal year 2000 budget seeks $5.3 billion for Head Start to serve an additional 42,000 children and their families. This is an increase of $607 million over fiscal year 1999, providing a total of 877,000 children a Head Start experience. Reauthorization of legislation supports doubling the size of Early Head Start by fiscal year 2002. Human sciences faculties collaborate extensively with community Head Start administrators providing expertise on program development and management, advocacy, and support for private and public collaborative efforts to provide quality child care. In return, Head Start programs provide learning opportunities for child development researchers and educators.

The budget request contains $1.2 billion in discretionary child care funds in fiscal year 2001, due to advance appropriation, an increase of $183 million over fiscal year 1999. The funds will support affordable, quality child care for low-income working parents. Ten million dollars will be set aside for research, demonstration and evaluation activities. Human sciences faculties are well qualified to support these activities.

The fiscal year 2000 budget requests $27 million for social services research, of which $6 million is discretionary funding. The BOHS urges support for these funds to support research and evaluation efforts focused on families transitioning from welfare to work, promoting responsible parenthood, and fostering child well-being. These findings are key to welfare reform strategies and family and child well-being outcomes.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The fiscal year 2000 budget requests $3.1 billion for CDC, a $201 million or 7 percent increase over fiscal year 1999. The BOHS is especially supportive of the food safety initiative, a collaborative effort with FDA, and USDA. The budget proposes $29.5 million for this effort, an increase of $10 million or 51 percent increase over fiscal year 1999. CDC will expand its public health labs' ability to fingerprint DNA of microorganisms. Human sciences faculties support this effort and are in a position to help expand risk assessment studies of producers, processors, food handlers, and consumers. Education programs must be based upon an understanding of producer, processor, handler and consumer actual practices; perceptions of risk, and levels of tolerance for risk relative to food safety.

The BOHS strongly endorses continued support for the Childhood Immunization Initiative, with a goal of 90 percent of all 2 year olds receiving a full series of vaccines. Successful programs of immunization and education for disease prevention are conducted by human sciences extension faculty in conjunction with local health departments and schools.

ADMINISTRATION ON AGING (AOA)

The BOHS supports the fiscal year 2000 request for $1.0 billion, an increase of $167 million over fiscal year 1999. Human sciences faculties are engaged in research and education programs for family and corporate caregivers, education for elderly in resource management and estate planning, nutrition education for individuals and congregate meal providers. The growing segment of this portion of the population requires research and education as well as policy development support.

We applaud the HHS agency for well targeted initiatives in the fiscal year 2000 budget request. Researchers and extension educators represented by the Board on Human Sciences contribute significantly to the programs addressed in this budget. Support for this budget can help assure our contribution and that of others. Thank

you for your attention to our commentary. We wish to work with the Congress and HHS in solving American health and human service problems.

PREPARED STATEMENT OF DR. STEPHEN REINGOLD, VICE PRESIDENT, RESEARCH PROGRAMS, NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and distinguished members of the subcommittee, I appreciate the opportunity to speak before you today. My name is Dr. Stephen Reingold and I am the Vice President of Research Programs for the National Multiple Sclerosis Society. The Society is the world's largest private voluntary health agency devoted to the concerns of all those affected by MS. In my position, I oversee the Society's portfolio of basic and clinical research projects. I also administer the Society's decision-making process to fund research projects—the peer review process. Throughout the Society's 53-year history, our number one priority has been research to understand MS and apply this knowledge to the development of new treatments and a cure. Cumulatively, the Society has expended over $260 million in research funds in the United States and abroad. Our current annual budget for research exceeds $20 million. This represents the largest privately funded program of basic, clinical, and applied research and training related to multiple sclerosis in the world. We clearly understand the difficulty of meeting the overwhelming need for biomedical research and the daunting task of allocating limited resources among many worthy research projects.

When testifying before you in previous years, an individual with MS represented the Society and explained the importance of research conducted at the National Institutes of Health to progress in developing treatments or a cure. This year, in addition to emphasizing the importance of NIH basic and clinical research to all people with chronic illnesses and disabilities, we would like to highlight our solid working relationship with NIH. Indeed, NIH and the National MS Society collaborate to further biomedical research and to end the devastating effects of MS.

The openness of NIH to information exchange, cooperation and collaboration with interested constituents enhances the agency's ability to accomplish its mission of uncovering new knowledge that will lead to better health for everyone. For organizations like ours with a stake in the work of NIH, there are new opportunities to gain and share information. To members of the subcommittee, we point to these opportunities as evidence that increased federal funding of NIH is a sound scientific and economic investment for people with MS and for the wellbeing of all Americans. It is simply good public policy.

MS is an often progressive, degenerative disease of the central nervous system, unpredictable in its course, and devastating in its impact. It can cause spasticity, tremor, abnormal fatigue, bladder and bowel dysfunction, visual problems and mobility impairment. The disease usually is diagnosed between the ages of 20 and 40—but is life-long. Many people with MS live thirty years or more with constant unpredictability and increasing disability. MS affects more than twice as many women as men, can result in loss of employment and loss of a place in society and the community. Recent studies sponsored by the MS Society show that the annual cost to each affected individual as a result of MS averages $34,000, and the total cost can exceed $2 million over an individual's lifetime. For all people with MS in the United States—some third of a million individuals, the annual cost is nearly $9 billion. Ending the devastating medical, personal and financial effects of this unpredictable disease is completely dependent upon the discovery of safe and effective treatments that halt progression of the disease and reverse its symptoms.

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY AND THE NATIONAL INSTITUTES OF HEALTH

National Institute of Neurological Disorders and Stroke

The National MS Society has had a long and productive relationship with NIH, particularly with the National Institute of Neurological Disorders and Stroke (NINDS). Our founder, Ms. Sylvia Lawry, spearheaded the effort that led to the creation of the neurology institute at NIH in 1950, when President Truman signed the bill into law that established the former National Institute for Neurological Diseases and Blindness, now NINDS. Since then, the Society has had a very positive working relationship with the institute—a vital link for us since NINDS currently funds approximately 75 percent of the MS-related research at NIH.

The Society works with NINDS to coordinate grant funding. In cases where scientists seek support for projects from both NINDS and the Society, we have had fruitful negotiations with the agency to assure appropriate levels of funding.

Intramural scientists from NINDS serve on our scientific advisory committees and help the Society make our research project decisions. Dr. Henry McFarland, Chief of the Neuroimmunology Branch at NINDS, chairs our senior Research Programs Advisory Committee, the panel of experts that oversees all of our research activities, and specifically reviews funding decisions made by primary peer review committees. Dr. Roland Martin, also in the Neuroimmunology Branch of NINDS, serves as a primary scientific reviewer. These outstanding scientist/physicians dedicate their volunteer time to help the Society make its research funding decisions, and to help ensure that the work of the Society and that of relevant parts of NIH are in concert, and not in opposition.

We were pleased this past year to welcome the new director of NINDS, Dr. Gerald Fischbach. And we were honored when he asked us to provide comments on the new strategic priorities at NINDS for fiscal year 2000, a planning initiative that Dr. Fischbach intends to conduct annually. As some of you may know, NINDS is planning to focus its resources in the coming year on seven crosscutting topics of wide importance in neurological disease. These areas—which relate to nervous system function, structure, and understanding and treating neurologic disease—target both basic research knowledge and applied clinical development. Each of these areas is of vast importance to neurologic disease in general, and each of them has direct applicability to multiple sclerosis. The following focus areas are of greatest importance to the MS community:

—Neurodegeneration, or studies of brain cell death, relates to nerve and even immune cells within the central nervous system in MS as well as other diseases.

—Genetics, and particularly the genetics of neurologic disease, is ripe for explosive discovery. The difficulty of unraveling the genetic basis of disease susceptibility when a number of genes are involved is enormous, and has direct impact on MS and related neurological conditions. The tools to tackle this huge problem are increasingly available, and increasingly available at NIH.

—Development of the nervous system and repair of damaged nervous system tissue has wide application across many neurological disorders including MS. All of the techniques that may be brought to bear on Parkinson's disease and spinal cord injury may be highly relevant to MS. This area could be ripe for an interdisciplinary research effort among basic and clinical scientists from a variety of disease areas—research that can best be facilitated by NIH.

—The NINDS plan stresses experimental therapies and clinical trials. We applaud this. We believe that NINDS can play a very important role in supporting clinical trials for agents that normally would not be candidates for corporate development.

—Finally, we are excited about the NINDS planned focus on collaborative relationships with other federal agencies, voluntary health agencies, and the private sector. Our experience to date suggests that such relationships will be "win-win" situations for all agencies and the patients we serve. We are eager to explore such opportunities.

National Institute of Allergy and Infectious Diseases

While MS is a neurological disease, the root problem in MS is dysfunction of the immune system. Therefore, the Society fosters close working relationships with the primary institute charged with studies of the immune system, the National Institute of Allergy and Infectious Diseases (NIAID). NIAID funds about 25 percent of the MS-related research at NIH. The Society benefits from a variety of interactions with NIAID:

—Dr. David Marguelies, in the intramural Laboratory of Immunology at NIAID, is a primary scientific reviewer of funding requests for research projects at the MS Society.

—We are currently participating in the NIH Autoimmune Disease Coordinating Committee that is assessing federal and non-federal support of autoimmune disease research and plotting a dynamic future research plan.

—Staff representatives of NIAID contributed enormously to the Society's recent targeted analysis of gender differences in MS and other autoimmune diseases.

—NIAID has an outstanding record of collaboration on projects with other health organizations and we welcome the opportunity to work more closely with NIAID in such efforts in the future.

Relationships with other sections of NIH

The MS Society also has close ties with other NIH entities. Ms. Laura Cooper, who serves as Independent Living Consultant for the Society, is chair of the National Advisory Board on Rehabilitation Research which advises the National Cen-

ter for Medical and Rehabilitation Research (NCMRR) on essential issues such as rehabilitation and quality of life for disabled individuals.

RECOMMENDATIONS FOR FUNDING

The National Multiple Sclerosis Society believes that in order to take advantage of current opportunities in biomedical and rehabilitation research, Congress must continue the trend set in last year's appropriation for NIH. A further 15 percent increase in NIH funding for fiscal year 2000 would bring us closer to doubling NIH budget by 2003. In order to pursue cutting edge research, the Society recommends that this translate into a parallel 15 percent increase for NINDS and NIAID, the primary institutes that conduct nearly all of the MS-related research undertaken by the federal government.

SUMMARY

NIH plays THE major role in maintaining our country's preeminence in the biotechnology industry and provides world-wide leadership in health research and discovery. The National MS Society could advocate for MS specific research and funding at NIH, but we do not. Rather, we recognize that new discovery and breakthrough findings could come from almost any area of biomedical research and could apply to the primary concern of our members: finding a cure for MS. We thus encourage Congress to focus on NIH as a whole, and on agencies of particular relevance to our concern, knowing that a well-funded federal research enterprise will benefit all of us. Continuing the 15 percent annual increase in funding through 2003 is an extraordinarily good use of federal resources and we encourage you to do whatever you can to make this a reality.

Thank you for the opportunity to testify.

PREPARED STATEMENT OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

I. SUMMARY OF RECOMMENDATIONS

The American Gastroenterological Association ("AGA") urges Congress to increase funding for medical research on digestive diseases and disorders through budgetary increases to the National Institutes of Health ("NIT"), Centers for Disease Control and Prevention ("CDC"), and the Agency for Health Care Policy and Research ("AHCPR").

Specifically, the AGA encourages Congress to provide at least a 15 percent increase over fiscal year 1999 for NIH, raising the funding levels from $15.612 billion to $18 billion, as recommended by the Ad Hoc Group for Medical Research Funding. Within NIH, the AGA recommends a 15 percent increase for the National Institute of Diabetes and Digestive and Kidney Diseases ("NIDDK"), the National Cancer Institute ("NCI"), and the National Institute of Allergy and Infectious Diseases ("NIAID"). These increases would allow for further research on the diagnosis, treatment and cure for debilitating and devastating digestive diseases.

The AGA also urges Congress to:

—Increase funding for the CDC from $2.9 billion to $3.9 billion for fiscal year 2000, an increase of 34.5 percent, as recommended by the CDC Coalition.

—Endorse the Friends of AHCPR recommendation to increase funding 31.5 percent over fiscal year 1999 for AHCPR from $171 million to $225 million.

II. MEDICAL RESEARCH RECOMMENDATIONS

The AGA appreciates the opportunity to present its views regarding fiscal year 2000 appropriations for NIH, CDC, and AHCPR. The AGA is the nation's oldest, not-for-profit specialty medical society, consisting of over 10,000 gastroenterologic physicians and scientists who are involved in research, clinical practice, and education on disorders of the digestive system. As the nation's largest and leading voice of the gastrointestinal research community, the AGA is uniquely qualified to advise Congress on the current status of federally-supported digestive disease research programs and the areas in need of further research.

Gastrointestinal cancer, foodborne illness, gastroesophageal reflux ("GERD") and ulcers, motility disorders, inflammatory bowel disease, and hepatitis C account for the majority of digestive illnesses, impacting the lives of millions of Americans. They affect more than half of all Americans during their lifetime, ranking second among all causes of disability due to illness in the United States. These diseases annually result in over 200 million sick days, 16.9 million lost school days, and 10 million hospitalizations. In some of these areas, medical research has brought us

close to developing lifesaving treatments and cures. Yet, in others, we still lack even a basic understanding of the cause and transmission of the disease. This testimony focuses on these serious health problems and makes recommendations on how Congress should allocate this country's precious medical research dollars.

Gastrointestinal cancers

Sadly, 131,000 Americans will die from these cancers. The most common cancers involve the colon/rectum, stomach/esophagus, pancreas, liver/intrahepatic bile duct, and gallbladder.

—It is estimated that 129,400 new cases will be diagnosed this year with approximately 56,000 Americans projected to die from this disease in 1999. Colorectal cancer is linked to age with over 90 percent of people diagnosed being over 50 years old. As such, treating this disease presents a huge cost to the Medicare program. Further, this disease strikes men and women equally but is more common among and associated with higher mortality rates in African Americans.

—In this year alone, nearly 22,000 Americans will be diagnosed with stomach or gastric cancer; 13,500 will die of it. A slightly lower number of people, 12,500, will be diagnosed with esophageal cancer this year. This cancer is three times more prevalent in men than women, and in African Americans than Caucasians.

—The incidence of liver cancer is increasingly dramatic due to the epidemic of chronic hepatitis C. Males have disproportionately higher incidence and mortality rates for this cancer as compared to females.

—More females are diagnosed and die from this cancer as compared to males.

The good news is that biomedical research, basic and clinical, has yielded increasingly positive cancer survival rates when patients' conditions are detected early. For example, 90 percent of people who develop colorectal cancer can be effectively treated if the disease is caught sufficiently early. This high survival rate is related to the slow growth of the cancer. Colorectal cancer develops from polyps or slow growing, grape-like growths on the colon and rectum, which become cancerous over time. The key to prevention lies in removing the polyps prior to the development of cancer, making screening imperative especially since many patients are asymptomatic. Unfortunately, only 40 percent of Americans are screened regularly. Thankfully, Medicare's new colorectal cancer screening benefit will help doctors improve the early detection rate. Improved screening alone, however, is not sufficient. We need additional research to understand the cause of these cancers and identify treatments for those whose illness is not detected early enough. Specifically, we encourage Congress to promote research into identifying the genes associated with these types of cancers.

Researchers have identified a genetic link to gastrointestinal cancers in 20 percent to 30 percent of cases. Research shows that a genetic mutation at one generational level continues to mutate at succeeding generational levels, increasing a person's likelihood of developing cancer. Funding for additional research in this area is extremely important and should focus on:

—The genetic aspects of gastrointestinal cancer including the potential identification of other genes;

—Diagnostic tests for genetic abnormalities and prevention;

—Environmental factors relating to the development of this disease, such as diet; and

—The development and treatment of Barrett's syndrome (a precursor to the development of lower esophageal/upper stomach cancer) in patients with GERD.

Agencies with potential interest in this area include NIH, CDC, and AHCPR. Within NIH, various institutes and offices should participate in this research including the NIDDK, NCI, National Human Genome Research Institute ("NUGRI"), National Institute of Environmental Health Sciences ("NIEHS"), National Institute on Aging ("NIA"), National Institute on Alcohol Abuse and Alcoholism ("NIAAA"), Office of Research on Minority Health ("ORE'), and Office of Research on Women's Health ("ORWH").

Foodborne illness

Some 6.5 to 33 million Americans suffer from foodborne illnesses each year, and 9,000 people die from these illnesses annually. Poor reporting of foodborne incidents causes the wide-ranging estimates, but it is clear that outbreaks of foodborne illness are increasingly commonplace: spread through swimming pools in Georgia; outbreaks in Chicago transmitted through milk; and infestations in day care centers. The more common pathogens include the following list.

—Salmonellosis, a bacterial infection triggered by , will cause between two and four million cases of illness this year.

—0157:H7 (the pathological strain of the bacterium) is estimated to cause 10,000 to 20,000 cases of illness annually with 250 deaths and economic losses of more than $200 million per year.
— causes a bacterial infection known as Shigellosis or dysentery, which is expected to cause 18,000 confirmed cases per year.
—Approximately 10,000 cases of foodborne illness due to infection with the bacterium are reported annually to the CDC with 500 annual deaths attributed to this pathogen.
—The protozoan C will cause cyclosporiasis in an estimated 1,120 cases this year.
— , a bacterium, will cause serious illness in approximately 1,100 people resulting in death for 250 people this year.
—C, a protozoan, has a prevalence rate of two percent but is estimated to have infected 80 percent of the population at some point during their lives.

Foodborne illness typically has an oral-fecal route of transmission with people getting sick from eating contaminated food or drinking infected water. Most foodborne illnesses attack the gut causing gastrointestinal symptoms such as anorexia, nausea, vomiting, diarrhea, bloody diarrhea, and abdominal discomfort. The resultant loss of electrolytes and fluids leads to dehydration and shock, and if not treated, death from vascular collapse and renal failure.

Listeriosis is particularly alarming because of its close association with processed foods. It is more resistant to heat and acidity than most pathogens and does not change the taste or smell of food, making it difficult to suspect, trace, or eradicate. Additionally, listeriosis presents as a flu-like illness with fever, chills, fatigue, nausea, vomiting, diarrhea, severe headache, stiff neck and occasionally bacterial meningitis. Because of these flu-like symptoms, many people infected with this bacteria do not know that they have it until the disease has progressed to advanced stages resulting in high mortality and morbidity rates. As a result, 20 percent of people with listeriosis die from it. Pregnant women are twenty times more likely to get listeriosis with potential results including miscarriage, fetal death/stillbirth, septicemia, meningitis or death in the newborn. Further, people with acquired immunodeficiency syndrome ("AIDS") are 300 times more likely to be infected with this illness than others with healthy immune systems.

Those populations at-risk for severe repercussions from foodborne illness include those with decreased immune systems, pregnant women and fetuses, young children, elderly, those taking antibiotics and antacids, and those with inadequate access to health care such as the homeless, migrant farm workers, and those with low socio-economic status.

We applaud Congress for its increasing awareness of and concern with the problems associated with foodborne illness, having in recent years enacted legislation and appropriated funds aimed at preventing bacteria from entering our food and water supplies through enhanced inspection programs. Moreover, current efforts would do precious little should the United States be the object of a deliberate bioterrorist attack on the nation's food or water supply. As such, we encourage Congress to channel additional resources into research for finding cures for people contaminated by foodborne pathogens.

The AGA recommends that Congress encourage the NIH, including NIDDK and NIAID, and others conducting foodborne illness research like the United States Department of Agriculture ("USDA") and the CDC to redirect their focus to concentrate more intensively on covering treatments for foodborne illness. Currently, the NIDDK, the NIAID, and the American Digestive Health Foundation ("ADHF"), a partnership sponsored in part by the AGA that supports research and education in digestive diseases, are working together to fund an RFA focused on foodborne illness research. However, this RFA alone is not enough. Additional research is needed in this important area. The AGA thus urges Congress to support research in the following areas.

—The reaction of the gut. The research currently being performed has focused on the kidney where few people are affected but the mortality rate is high. Stopping the disease when it is initially confined to the gut, however, would prevent the kidney from even being affected.
—The pathogenesis of the disease to: (a) identify the pathogens, (b) understand contamination and transmission patterns, (c) understand how pathogens translate into disease in humans, and (d) determine the reason for antibiotic resistance.
—The development of animal models to understand how the pathogens cause disease and to develop treatment.
—The invention of vaccines or substances that bind with the toxins to prevent the illness.

This type of research crosses many institutes at NIH including NIDDK, MAID, NIA, and the National Institute of Child Health and Human Development ("NICHD"). Federal agencies beyond the NIH, including the USDA, CDC, and the Department of Defense are also performing valuable research in these areas.

Motility disorders

Eight to seventeen percent of Americans suffer from functional gastrointestinal disorders, making it a major cause of morbidity and mortality from digestive illnesses, particularly among females.

We appreciate the work of Congress and NIDDK on a motility RFA. However, further research is needed in this area both due to the high prevalence of this disease as well as the lack of knowledge on how to identify, diagnose, and cure the disease. Irritable Bowel Syndrome ("IBS"), the most common motility disorder, is especially troubling because a patient does not present with any pathognomonic symptoms or laboratory findings of the disease, making diagnosis and treatment extremely difficult. IBS research focused on the following areas will do much towards alleviating these problems:

—Understanding how the enteric nervous system works;
—Clinical descriptions and epidemiological studies of patients with IBS including family backgrounds;
—Genes that determine susceptibility and resistance;
—Brain interactions with the gut; and
—Virus foodborne initiators that appear to cause IBS in previously unaffected individuals.

A lack of a basic understanding of IBS has made drug manufacturers reluctant to fund research. If more federally funded research was focused on IBS, it would stimulate more private-public partnerships, and lead to advances in medical knowledge.

Inflammatory bowel disease (Ulcerative Colitis and Crohn's disease)

Unlike IBS, inflammatory bowel disease ("IBD") involves an inflammation of the bowel. One type of IBD is Crohn's disease, which primarily involves the colon and small bowel. The other is ulcerative colitis affecting the inner lining of the large intestine. IBD usually begins in early adulthood and persists throughout life with remissions. IBD affects people in the prime and most productive years of their lives and results in substantial morbidity and economic loss to them and society. People with IBD experience abdominal pain, fever, bowel sores, intestinal bleeding, anorexia, weight loss, fullness, diarrhea, constipation, and vomiting. In severe cases, the patient can hemorrhage or contract sepsis/toxemia resulting in death. The cause of IBD is unknown; it may be a virus or bacteria that alters the body's immune response causing an inflammatory reaction in the intestinal wall. Studies on the cause of IBD are desperately needed in order to have a better understanding of the disease and work towards more effective management and treatment.

Hepatitis C

Viral hepatitis is caused by six different viruses (commonly labeled A, B, C, D, E, and G), each of which can trigger acute hepatitis. Only hepatitis B, C, D, and G cause chronic hepatitis with hepatitis C accounting for 60 percent to 70 percent of all chronic cases of hepatitis. A . This disease is projected to cost $600 million a year in terms of medical care and work loss, excluding transplantation costs. Between 8,000 to 10,000 people are expected to die from HCV this year with the death rate expected to triple over the next decade. It ranks second only to alcohol abuse as the cause of cirrhosis (i.e., liver cell damage and scarring) and liver disease, and is the leading cause for liver transplants in the United States. Minority populations have a higher prevalence of this disease with the rate being 1.5 percent in non-Hispanic Caucasians, 3 percent in African Americans, and 2.1 percent in Mexican Americans.

Acute hepatitis C results in a chronic infection in over 85 percent of the cases with most contracting chronic liver disease. The chronic infection associated with HCV is often asymptomatic, making detection extremely difficult. In fact, many people do not even know they are infected. This is so even though the virus can be easily detected through a simple blood test. Twenty-five to thirty percent of people infected with HCV develop symptoms ranging from mild to moderate problems of jaundice, fatigue, abdominal pain, loss of appetite, intermittent nausea, and vomiting to more severe, life-threatening conditions such as liver disease, cirrhosis, and end-stage liver disease, including cancer.

Fortunately, Congress has vigorously supported HCV research. Past NIH research has provided some hope in terms of treatment. Long-term remission was attained in up to 40 percent of HCV patients receiving alpha interferon along with ribavirin,

an anti-viral agent. Moreover, NIDDK and NIAID recently issued an RFA focusing on HCV.

Despite this support, treatment is highly effective in only 15 percent to 30 percent of patients. Further, no vaccines are currently available to prevent hepatitis C. Accordingly, more research is needed. The AGA urges Congress to encourage the NIH to support the following areas of research:

—The molecular biology of HCV;

—A longitudinal study on the normal clinical course of hepatitis C and factors resulting in progression to cirrhosis and liver cancer;

—Epidemiological studies on hepatitis C and alcohol consumption; and

—The interaction between HCV and other diseases such as diabetes and AIDS.

This research would enable the development of therapies to stop the progression of the disease, a vaccine to prevent transmission of HCV, and strategies for educating at-risk groups.

NIH groups specifically interested or affected by this disease include the NIDDK, NIAID, NCI, ORMH, National Heart, Lung, and Blood Institute ("NHLBI"), Office of AIDS Research ("OAR"), and National Institute on Drug Abuse ("NIDA"). All should be encouraged to support additional research into this area.

Gastrointestinal centers

Currently, twelve centers exist with a thirteenth center planned for fiscal year 2000. These centers conduct basic and clinical research on digestive, hepatic, and pancreatic disorders. They have been highly successful in expanding medical knowledge on pancreatic disease, genetic diseases (e.g., hemochromatosis) and gene therapy, pediatric gastrointestinal diseases, hepatitis C, IBS, IBD, inflammatory cytokines, and food safety. A 15 percent increase in funding for NIDDK over fiscal year 1999 would allow full funding and expansion of these centers.

III. FUNDING RECOMMENDATIONS

The diseases, illnesses, disorders, and syndromes described above continue to take a huge toll on the American public and economy. The AGA appreciates Congress' commitment to biomedical research, to the NIH in recent years, and to digestive diseases research in particular. However, more effort is needed. Many of the illnesses described above are only now beginning to emerge as the next epidemic (e.g., HCV). For others, like certain gastrointestinal cancers, research advances have placed the hope of eradication within our grasp. In either case, now is not the time to shortchange this country's vital research programs. Congress must keep up the momentum it has started, and in some cases, devote even more resources.

We encourage Congress to ensure that the federal biomedical research infrastructure has adequate resources to appropriately pursue research opportunities in the areas discussed above by fulfilling the funding recommendations outlined below.

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The AGA appreciates the opportunity to present its views on the fiscal year 2000 appropriations. Please call Michael Roberts, Vice President of Public and Government Relations at the AGA, at (301) 941–2618 if you have further questions.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS

Founded in 1976, ANAD is our nation's oldest non-profit organization dedicated to alleviating the problems of the following eating disorders; anorexia nervosa, bulimia nervosa and binge eating disorder. Our testimony is on behalf of the estimated 7,000,000 women and 1,000,000 men suffering from serious and often life-threatening eating disorders in America today. ANAD's education, early detection, and prevention programs provide models for low cost outreach services that benefit hundreds of thousand Americans. ANAD programs are free and demonstrate that effective helping strategies need not be expensive.

Eating disorders are a form of severe mental illness with a significant physical impact and many complex causes including psychological, familial, and sociocultural components. And as some recent authoritative studies have revealed, genetic and biological components. Although eating disorders develop primarily before adulthood, they can be found in older women, in men and boys and across any racial, ethnic and socio-economic boundaries. Statistically, death and disability rates for eating disorders are among the highest of all mental illnesses. The National Institute of Mental Health estimates that 10 percent of victims die. NIMH also reports that 1

in every 100–200 adolescent girls will be afflicted with an eating disorder. Further, 80–90 percent of the onset of disordered eating behaviors occurs by the age of 20 with 43 percent under the age of 15. Fortunately, with appropriate medical and psychological treatment, individuals do recover from these terrible illnesses. Treated early, eating disorders are curable and at lower cost emotionally and monetarily.

Eating disorders as a phenomena are culturally embedded in the experience of American young adulthood. Studies indicate that the incidence of eating disorders is growing rapidly. This is not surprising, given our culture's obsession with thinness and billion dollar industries devoted to weight loss which contribute to the initiation and progression of these destructive behaviors. And while these problems are especially acute for our nation's girls, they are shared with a growing number of boys.

In an article published late last year, Dr. Daniel Krowchuk, a pediatrician at Wake Forest University School of Medicine, documented his research with over two thousand sixth, seventh and eighth grade students on weight control issues. In his study Dr. Krowchuk found that almost 10 percent of the girls and 4 percent of the boys surveyed reported vomiting or using laxatives to lose weight. Dr. Krowchuk concluded, "Younger adolescents trying to lose weight engage in a variety of problem dieting and weight loss behaviors that can compromise health and may be associated with eating disorders."

Dr. Krowchuk's study and others like it is the reason that my focus today is on education and prevention. There is concern among some in the medical and academic communities that previous educational programs aimed at prevention of eating disorders have been tainted by their tendency to, in essence, teach youngsters about the unhealthy diet practices utilized by anorexics and bulimics. This might possibly serve to advertise those destructive behaviors to some susceptible youngsters where the opposite is intended.

For this reason we ask Congress to appropriate a minimum of $10,000,000 for the development and implementation of comprehensive education and prevention programs that promote correct notions about nutrition, body development and growth through educational wellness for all of America's school-aged children and early identification of those at risk for these diseases.

To be truly effective, prevention programs should focus on teaching children the skills necessary to cope with the emotional complexities of life in a positive, life and self-affirming way with an emphasis on nutritionally sound eating practices. Our young people need to learn self-respect, appropriate responses to both successes and failures, and ways of handling change without succumbing to an unhealthy relationship with food. Children and adolescents should be discouraged from embracing the myth that happiness hinges on attaining a "perfect" body as defined by the popular media.

Eating disorders are multi-causal, yet much about the nature of these disorders still remains unknown. For this reason, we also ask Congress to increase current funding by an additional $10,000,000 for the research necessary to further investigate the causes of these disorders. One of the keys to helping the predominantly teenage victims of eating disorders is by identifying the specific population at risk for developing these diseases. Research which results in discerning the specific cause or causes for eating disorders renders three great results 1. better treatment; 2. development of effective prevention programs; and 3. development of focused education programs. The biological component of eating disorder causation which has gotten significant press recently particularly warrants further study. This funding is essential, if we are to develop truly effective prevention programs.

In order to ensure that federal monies earmarked for eating disorders research are used solely for this purpose, funds allocated should have built within them a system for monitoring their application and use.

We ask the members of this subcommittee and Congress to enact legislation that provides funding aimed at preventing another generation of youth from developing eating disorders in rapidly increasing numbers. This legislation would also fund research to get to the root cause of eating disorders. Thus, strengthening the effectiveness of eating disorder treatment protocols.

Thank you.

PREPARED STATEMENT OF THE FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Mr. Chairman and members of the Subcommittee: The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) wishes to thank the subcommittee for this op-

portunity to testify regarding funding for skin disease research and the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS).

F.I.R.S.T. is a voluntary organization dedicated to providing support, information, education and advocacy for individuals and families affected by ichthyosis. F.I.R.S.T. supports research into causes, treatment and a cure for ichthyosis.

Ichthyosis is a family of genetic skin diseases characterized by dry, thickened, scaling skin. These diseases are caused by genetic defects that are usually the result of genetic inheritance. Currently, there is no cure for Ichthyosis, and there are no truly effective treatments.

Some forms of ichthyosis cause the skin to be very fragile and blister easily. Scaling and flaking are continuous. The skin is tight and cracked. The palms and soles can be thick, making something as simple as holding a pencil or as natural as walking difficult and painful. Overheating is dangerous and infections are a constant threat.

Our children are sometimes hospitalized for infections. Simple medical procedures are complicated. Days and activities are planned around skin care. Stares and questions from strangers are common. While the physical aspects of ichthyosis are obvious, the blows to ones self esteem can be even more damaging. Currently, ichthyosis is a life-long battle. Hopefully, this will change in the future.

We recognize this Subcommittee's strong history of bipartisan support for medical research funding and the NIH. In 1992, researchers identified the sites of two genetic mutations that account for 70 percent to 80 percent percent of all cases of EHK. Since that time, genetic mutations that cause other forms of ichthyosis have been identified and scientists and physicians have a much better understanding of the disease process.

We are excited about this progress, and about the current research into gene therapy. We are hopeful about the possibility for an effective treatment or cure on the horizon, but at this point it is still just hope. We continue to be frustrated by the lack of effective treatment options.

We are also discouraged by the lack of available testing facilities. Genetic testing is possible today for the types of ichthyosis for which the specific mutations have already been identified. However, with the exception of one of the milder forms of ichthyosis, (Recessive X-linked Ichthyosis) there are no clinical laboratories that offer these services. These tests are complex and time consuming. However, they can provide valuable information to affected families. They can also help to plan appropriate intervention for those at risk for labor and delivery problems and premature birth that are common with some forms of ichthyosis.

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) urges the Congress to provide $354 million in fiscal year 2000 for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, a 15 percent increase over fiscal year 1999. We believe that this increase is necessary to allow NIAMS to support a greater number of worthy research projects, conduct more clinical trials and expand it's intramural research program.

F.I.R.S.T. also supports increased investment in translational research, which would build upon this new scientific knowledge to develop practical applications for those with ichthyosis and other skin diseases. The recent discovery of many of the genes involved in specific skin diseases is just the starting point for improving diagnosis and treatment.

In 1992 a member of F.I.R.S.T. testified before this committee regarding the need for a national registry. Today, as a direct result of your interest and support, we have the National Registry for Ichthyosis and Related Disorders. Many of our members, and their physicians, have participated in the detailed enrollment process, and enrollment is proceeding at an ever increasing rate. The registry helps generate researcher interest in ichthyosis, and provides investigators with an essential tool—a pool of affected individuals with a confirmed clinical diagnosis. The availability of this pool of information results in significant savings in research time and dollars which would have normally been spent identifying eligible patient populations.

Current funding for the National Registry for Ichthyosis and Related Disorders expires in 1999, but the work of the registry must continue. Continued funding of the skin disease registries will ensure that these resources will be maintained and will continue to be a valuable tool for investigators.

On behalf of our members, those with ichthyosis and their families, we thank this Congressional Subcommittee for their time and attention.

Additional copies of this testimony can be obtained through the Foundation's web site: www.libertynet.org/ichthyos or by contacting F.I.R.S.T. at PO Box 669, Ardmore, PA 19003 (610) 789–3995.

PREPARED STATEMENT OF KELLY CARR, MANAGING DIRECTOR, MUSEUMS & UNIVERSITIES SUPPORTING EDUCATIONAL ENRICHMENT

Mr. Chairman, I appreciate the opportunity to put into the record this brief statement about Museums & Universities Supporting Educational Enrichment, better known as MUSEE. MUSEE is a 501(c)(3) not-for-profit organization, based in Philadelphia, which works with schools, libraries and cultural institutions to increase public access to the benefits of museum-based curriculum and computer technology.

The themes underlying MUSEE's initiatives and activities are embodied in the Elementary & Secondary Education Act in Title III (Technology & Education). Among other mandates, that Act, as you know, requires the Federal government to develop a long-range plan which outlines the effective use of technology in education. Included in the intent of the Act is an authorization for funding to encourage local partnerships among school districts, non-profit organizations and technology companies. The stated purpose of these consortia is to improve teaching and learning through the use of advanced technology, including "technological education to students as well as training of teachers".

MUSEE has three main goals which are congruent with the Elementary and Secondary Education Act: (1) to advance education at the elementary and secondary (and higher) education levels; (2) to stimulate public interest in educational and cultural institutions, and (3) to enhance cultural awareness within the educational arena and the public. In carrying out its mission in pursuit of those goals, MUSEE assists various institutions in preparing for future developments in education and the uses of technology.

Over the time of its existence, MUSEE has found that it can best accomplish its goal of serving the public by fostering information exchanges between educational institutions and technology companies. In turn, these exchanges generate new ways to better utilize technology for educational purposes.

MUSEE facilitates the information exchanges in a number of ways, including through the Internet and through special seminars. MUSEE also works with public institutions, in a consultant capacity, to create educational tools for use in elementary and secondary schools, and to archive resources for educational and cultural research. All of these institutions have benefited from their associations with MUSEE.

As you know, Mr. Chairman, MUSEE requested grant funding assistance in the fiscal year 1999 Labor, Health and Human Services, and Education Bill. Senate Report 105–300 (which accompanied the Year 1999 Labor, Health and Human Services, and Education Bill) contains language which stipulates that a $2,000,000 Technology Innovation Challenge Grant should be made available to MUSEE. The purpose of the grant, as noted in the language, is to assist in funding a traveling technology exposition which will travel throughout the country. The exposition will showcase technology software and instructional programs for teachers, students and other sectors of the population through on-site seminars on technology in the classroom.

As part of the required protocol for accessing the funds noted in the Senate Report, MUSEE has formed a consortium of local school districts and other non-profit entities, along with various multi-media companies. The exposition, for which the funds will be used, will begin in Philadelphia, then move to Chicago and ultimately travel throughout the Nation and beyond. MUSEE will continue to work with the Department of Education on this initiative.

The fiscal year 1999 funding will be devoted to the first phase of the exposition. In order to launch the next phase, MUSEE is requesting $2,000,000 in the fiscal year 2000 Labor, Health and Human Services Appropriations Bill. This second phase will provide the necessary assistance to bring the overall exposition initiative to full maturity.

Mr. Chairman, MUSEE has already acquired considerable support funds from the private sector. The Federal funding component is necessary to move the effort forward. If MUSEE receives the necessary Federal funds, the public-at-large, and particularly school children, will benefit from the MUSEE project through increased access to high technology learning tools. I urge you to fund this effort, as it is worthwhile for the future of education and in keeping with the intent of the Elementary and Secondary Education Act.

Thank you for this opportunity.

PREPARED STATEMENT OF THE BIOTECHNOLOGY INDUSTRY ORGANIZATION

The Biotechnology Industry Organization (BIO)[1] is pleased to submit this statement in support of increased appropriations for the National Institutes of Health (NIH). BIO represents over 860 biotechnology companies, academic institutions, and state biotechnology centers, in 47 states and more than 26 nations. BIO members are involved in the research and development of the life sciences including health care, agricultural, and environmental biotechnology products.

BIO supports a $2.3 billion—15 percent—increase in NIH funding for fiscal year 2000. This is in line with the proposal by the Ad Hoc Group for Medical Research Funding. BIO is the only representative of industry on the Executive Committee of the Ad Hoc Group, a coalition of voluntary health groups, medical and scientific societies, academic and research organizations, and industry representatives. This proposed increase for fiscal year 2000 is the second step towards doubling the NIH budget by 2003. BIO recognizes the difficulty in achieving such a goal under the current spending limits, and therefore, encourages the Senate Appropriations Subcommittee to explore all possible options to identify the additional resources needed to support this credible goal.

BIOTECHNOLOGY INDUSTRY-NIH PARTNERSHIPS

The U.S. biotechnology industry, along with the NIH and its grantees, have a strong partnership which is crucial to promoting new product development. Federally-funded basic biomedical research must be transferred to the biotech and pharmaceutical industries for products to become available to patients.

The biotechnology industry mainly conducts applied biomedical research that explores ways to develop crude medical technologies into drugs and biologics. While the biotechnology industry conducts some basic research, it relies on NIH and its grantees to conduct the majority of basic research. Once NIH or its grantees discover a new technology from basic research, they license it to a biotechnology company. The biotechnology company then invests in applied research to produce a drug or biologic. Both NIH and the biotechnology industry play complementary and distinct roles in the drug development process; each role is essential for continued U.S. leadership in drug development.

The biotechnology industry is growing rapidly. Currently there are 82 biotechnology drugs and vaccines on the market helping over 100 million patients worldwide. Over the past four years, 75 of these medicines have been approved by the Food and Drug Administration (FDA), and now, more than 300 biotechnology medicines are in second and third stage clinical trials. These 300 medicines under FDA review are drugs for AIDS; breast, ovarian and prostate cancers; heart disease; Alzheimer's; genetic diseases such as cystic fibrosis and many other conditions.

In 1998, the biotechnology industry employed 153,000 people, a nine percent increase over 1997; recorded product sales of $13.4 billion, a 17 percent increase over 1997; and increased its market capitalization (value of its entire capital assets) from $41 billion to $97 billion over the past five years.[2]

The biotechnology industry is one of the most research-intensive industries in the world. A crucial factor contributing to this rapid growth is the enormous investment in research and development by biotechnology companies financed by private investors. In 1995, the five companies with the highest research and development budgets per employee were U.S. biotechnology companies. Biogen, Genetics Institute, Genentech, Immunex, and Amgen had R&D budgets per employee between $210,653.5 and $91,265.8.[3] (The R&D chart is located in Appendix I.) In 1998, the entire biotechnology industry invested $9.9 billion in research and development, a 16 percent increase over the previous year. Because only 3.5 percent (45 of approximately 1,300 companies) have product sales to fund research, biotechnology companies depend on venture capital and public market investors to fund their research. Furthermore, it is rare for biotechnology companies to make a profit. The biotechnology industry lost $5.1 billion, a 50 percent increase in losses over the previous year ($3.4 billion in losses). To date the biotechnology industry has never had a profitable year.

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[1] For further information contact Chuck Ludlam, Vice President for Government Relations or Brett Karcher, Government Relations Assistant 202–857–0244.

[2] Ernst & Young, Bridging the Gap: Ernst & Young's 13th Biotechnology Industry Annual Report, 1999 at 4. (1999); Ernst & Young, Reform, Restructure, Renewal: The Ernst & Young Ninth Annual Report on the Biotechnology Industry, 1995 at 2. (1996).

[3] "1995 R & D Scoreboard," Business Week 3 July 1995.

These negative balance sheets are understandable when one takes into account that, on average, it costs $300 to $450[4] million and takes, on average, 15.2 years from the time a new drug is discovered until it is approved by the Food and Drug Administration.[5] In short, producing cutting-edge medicines is an extremely expensive, risky, long-term undertaking which requires continued strong Federal government support for NIH.

Increased funding for NIH will generate more basic research which can be transferred to the private sector for commercialization. From 1996 to 1998 only 28 to 31 percent of all research grant applications, were funded.[6] In other words, over the last three years approximately 70 percent of NIH grants were unfunded, which was not due to lack of scientific merit. The vast majority of NIH grant applications meet the scientific requirements and would make significant inquiries into disease, if only the NIH budget were sufficient to support these scientific opportunities.

THE ROLE OF TECHNOLOGY TRANSFER

The partnership between NIH and its grantees and the biopharmaceutical industry stand at the center of the world's most productive biomedical research enterprise. This successful partnership is founded on the transfer of technology from NIH and its grantees to biopharmaceutical companies. Outlined below are fundamental technology transfer mechanisms that facilitates the transition of basic research into new drugs and biologics.

—NIH and NIH-grantees have entered into a broad array of research agreements and licenses. These agreements and licenses typically provide that intellectual property generated by NIH and NIH-grantees is licensed or sold to biotechnology and pharmaceutical companies in exchange for royalty payments on any sales.

—Licenses can be exclusive or non-exclusive (i.e. sold to one, or more than one entity). Each type of license may be appropriate depending on the circumstances. About 10 percent of NIH's licenses are exclusive. Academic researchers not engaged in research for commercial use are not affected by the existence of an exclusive license. The Association of University Technology Managers (AUTM) Licensing Survey, fiscal year 1997, found that universities executed 2,665 licenses and options of which 1,377 were exclusive (52 percent) and 1,288 were non-exclusive (48 percent);[7] U.S. hospitals and research institutes executed 361 licenses and options, of which 208 were exclusive (58 percent) and 153 were non-exclusive (42 percent);[8] and Canadian institutions executed 198 licenses and options, of which 139 were exclusive (70 percent) and 59 were non-exclusive (30 percent).[9]

An exclusive license gives a company a greater incentive to invest its resources in the development of technology and this means that the companies are able and willing to pay a higher royalty rate to the NIH or an NIH-grantee. Exclusive licenses are particularly appropriate in cases where substantial risk and expense are involved in the development of basic research into a marketable product.

—Central to these relationships are patents which ensure that the results of the university and industry investments are not misappropriated by those who did not make the investments. Without patent protection no company can persuade its investors to put their capital at risk, and NIH and its grantees would have no intellectual property to license. The patentability of inventions is determined by the Patent and Trademark Office under well-established guidelines.

—Universities filed over 4,267 new patent applications in fiscal year 1997 in the expectation that they could generate revenues in the form of licenses and royalties.[10] The availability of patents leads to an intense competition in the development of life-saving drugs, biologics and devices. Patients in need of new medicines and devices are the beneficiaries of this competition.

—Patents do not block university researchers from conducting research on patented inventions. These researchers are protected from a patent infringement

[4] DDT Vol. 3, No. 11 November 1998 at 487, published by Elsevier Science Ltd.
[5] "The Tufts Center for the Study of Drug Development, 1996—1997 Annual Report at 15.
[6] "A Resource Guide, The Ad Hoc Group for Medical Research Funding" February 1999, at v.
[7] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 94.
[8] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 146.
[9] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 165.
[10] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 1.

law suit by an "experimental use" exemption because they are not competitors with a commercial motivation.

ECONOMIC BENEFITS OF THE PARTNERSHIP

An often undervalued benefit of the NIH-biotechnology industry partnership is the substantial increases in U.S. economic activity. An overview of economic benefits are listed below.

—In 1998, NIH received in royalties approximately $40 million (from 215 licenses). (See Appendix III.) This income helps to fund additional research.

—In 1997, of all federally funded university grantees the top ten recipients of royalty income include: University of California System ($67.3 million), Stanford University ($51.7 million), Columbia University ($50.3 million), Florida State University ($29.9 million), Massachusetts Institute of Technology ($21.2 million), Michigan State University ($18.3 million), University of Florida ($18.2 million), W.A.R.F/University of Wisconsin-Madison ($17.2 million), Harvard University ($16.5 million), Carnegie Mellon University ($13.4 million).[11] This income also helps to fund additional research.

—In 1996, separate from paying licensing royalties, industry sponsored $219 million in research at U.S. universities, hospitals and research institutes, the overwhelming portion of which is in biomedical research.[12] (This research includes sponsorship of clinical trials such as $40 million at Massachusetts General Hospital and $33 million at the Mayo Clinic.) This income is vital to the biomedical research efforts of these institutions.

—Over 2,214 U.S. companies were formed between 1980 and 1997 (333 U.S. companies were formed in 1997 alone) as a result of a license of an academic invention.[13]

—An economic impact model developed by Association of University Technology Managers shows that, in fiscal year 1997, $28.7 billion of U.S. economic activity can be attributed to the results of academic licensing (the majority of which came from NIH), supporting 245,930 jobs. In fiscal year 1996, the comparable figures were $24.8 billion and 212,500 jobs.[14]

—These technology partnerships, and the patents on which they are based, are particularly important to small biotechnology companies. These companies tend to focus their research on breakthrough technologies that come from basic biomedical research. They also must have strong patent protection to justify the risks they take. Most of these companies have no revenue from product sales to fund research, thus, they depend on venture capital and public market investors. In 1998, the biotechnology industry lost $5.1 billion. Previous years have had similar financial losses (1997, $4.1 billion loss; 1996, $4.5 billion loss; 1995, $4.6 billion loss).[15] The biotechnology industry has never had a profitable year.

THREATS TO THE NIH-INDUSTRY PARTNERSHIPS

The effectiveness of the NIH technology transfer program has increased dramatically in recent years. The unconditional repeal of the "reasonable" price clause in April of 1995 has been critical to this success. (For a listing of statements from health policy experts in favor of repealing the "reasonable" price clause see the Appendix II.)

Congress should continue to support NIH's decision, and not reinstate the ill-conceived price review policy, by opposing H.R. 626, the Health Care Research and Development and Taxpayer Protection Act. To do so would jeopardize the gains we have seen in the effectiveness of the NIH technology partnership program. To expand this failed and counter-productive price review program to the NIH extramural program and the programs of other government agencies conducting or sponsoring biomedical research would further jeopardize the effectiveness of those programs and the entire biomedical research enterprise.

The repeal of the price review policy by NIH was both decisive and justified. Among biotechnology companies the repeal has substantially increased interest in collaborating with the NIH and other Public Health Service (PHS) agencies. It reas-

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[11] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 50.

[12] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 145.

[13] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 1.

[14] AUTM Licensing Survey, fiscal year 1997, Association of University Technology Manager, Inc. at 2.

[15] Bridging the Gap: Ernst & Young's 13th Biotechnology Industry Annual Report at 4.

sures companies who enter into collaborations with NIH and PHS grantees that their agreements will not be subject to a pricing clause in the future. The "reasonable price" clause prior to April 1995 deterred companies from collaborating with NIH and decreased NIH's ability to transfer its basic research into marketable products.

The principal technology transfer mechanisms are Cooperative Research And Development Agreements (CRADAs) and Bayh-Dole Agreements. (For a more detailed explanation of these technology transfer mechanisms, see Appendix IV.) Both agreements enable the NIH and its grantees to license technologies to biotech and pharmaceutical companies, and in return, the company pays NIH or its grantees royalty payments.

The positive impact of the repeal is seen by the fact that after it was passed, the number of CRADAs rose from a low of 31 in 1994 to 166 in 1998. The number of executed licenses grew from a low of 75 in 1993 to a high of 215 in 1998. Royalties also grew substantially, from $13.494 million in 1993 to $39.563 million in 1998. (These figures are in the Technology Transfer Activity chart in Appendix IV.) These figures demonstrate the wisdom of the NIH decision to repeal the clause and the necessity of not reinstating a similar provision which would undermine research.

In 1995 and 1996 amendments to the NIH appropriations bill were offered in the House of Representatives to reinstate the "reasonable price" clause. These amendments were decisively rejected.

Recently H.R. 626 was introduced. BIO opposes this measure and urges Congress to strongly fund NIH research and not to pass such a bill. BIO believes the NIH's mission is research, not the pricing of medicines developed. Issues of pricing or access should only arise once a medicine has been developed and approved by the FDA. Raising issues of pricing or access during the research stage is premature and counter-productive. It undermines the ability of our companies to convince investors to fund a collaborative research program with the NIH. When medicines are developed from NIH basic research, then NIH has fulfilled its mission and deserves praise—and royalties—for its fundamental contribution to the advancement of science and to the health of our Nation.

APPENDIX I: BUSINESS WEEK R & D SCOREBOARD 1995

Business Week [16] conducted the "1995 R&D Scoreboard" which measured the level of research and development investment per employee in U.S. companies. In this study, five of the top ten U.S. companies were biotechnology firms. The complete R&D chart is listed below.[17]

Rank	*Average Expenditures On Research Per Employee*
1. **Biogen**	$210,653.50
2. **Genetics Institute**	114,942.50
3. **Genentech**	112,029.80
4. **Immunex**	102,719.10
5. **Amgen**	91,265.80
6. S3	82,548.30
7. Adobe Systems	70,993.00
8. Platinum Technology	69,787.30
9. Cirrus Logic	68,745.60
10. Network Computing Devices	68,308.00

APPENDIX II: LIST OF STATEMENTS BY PUBLIC HEALTH OFFICIALS ON THE FAILED "REASONABLE" PRICE CLAUSE

Reasonable price clauses "discourage technology transfer and the development of new therapeutic products by imposing price restrictions that may limit the ability of any company to recover its costs of research and development. Royalty provisions or payments to reimburse the government laboratory for its costs or, in appropriate circumstances, the supply of clinical materials (rather than restrictions on the pricing of products) may be more appropriate mechanisms to fairly and appropriately compensate the government laboratory for the use of its technology in commercial development." Final Draft Report of the External Advisory Committee of the Director's Advisory Committee, The Intramural Research Program, National Institutes of Health, April 11, 1994.

[16] "1995 R & D Scoreboard," Business Week 3 July 1995.
[17] Companies in bold are biotechnology companies.

The NIH insistence on price controls "nearly ruined the system," said Dr. Steven Paul, the former scientific director of the National Institute of Mental Health and a creator of the NIH technology transfer program. Cited by Dr. Robert Goldberg in "Race Against the Cure: The Health Hazards of Pharmaceutical Price Controls," Policy Review, Spring 1994 (number 68) at 34.

A report by the HHS Inspector General noted that the controversy at NIH over CRADA pricing threatens support for the program (Office of Inspector General, Dept. of HHS, Technology Transfer and the Public Interest: Cooperative Research and Development Agreements at NIH (OEI–92–01100)(Nov. 93)). This report finds that the use of an arbitrary and unpredictable "reasonable price clause" is undermining the transfer of NIH patents to private companies. Many private biomedical research companies now refuse to participate in CRADAs. This fact undermines the rationale for appropriating so many billions of dollars to fund this basic research.

Dr. Bruce Chabner, Director of the National Cancer Institute's (NCI) Division of Cancer Treatment, in testimony at a congressional hearing last year discussed specific instances in which companies have discontinued projects or suspended CRADA negotiations because of concerns raised by the "reasonable pricing clause." Chabner noted that "Other companies have simply refused to become involved with the NCI in early drug development . . . . NCI has no doubt that companies will not accept the risks of investing large sums in the development of a government product if their freedom to realize a profit is restricted. These companies are not willing to put their corporate fate in the hands of a government-appointed committee of experts. There are less risky ways for companies to make a profit." Testimony of Dr. Bruce Chabner, Director of the Division of Cancer Treatment, National Center Institute, before the House Subcommittee on Regulation, Business Opportunities and Energy of the House Committee on Small Business (Jan. 25, 1993).

The Committee to Study Medication Development at the National Institute on Drug Abuse states that the "reasonable-pricing clause required in (DHHS CRADAs) in the last year has been identified by NIDA as a major deterrent to attracting private-sector partnerships..." The Committee "recommends a change in the reasonable pricing provisions of DHHS CRADAs so that licensees or manufacturers of medications know explicitly the ultimate pricing or pricing structure for their potential therapeutic agent." Development of Anti-Addiction Medications: Issues for the Government and Private Sector, Institutes of Medicine, 1994.

An article cites NIH officials attributing the price control clause for the precipitous decline in CRADAs. "Many pharmaceutical companies are reconsidering CRADAs, and NIH officials say four of the largest . . . have told NIH that they plan to forego new CRADAs unless the pricing clause is removed." Christopher Anderson, "Rocky Road for Federal Research Inc.", Science, 497 (October 22, 1993).

The Cancer Letter published a draft "Action Plan on Breast Cancer" developed from a recent NIH conference convened by Secretary Donna Shalala which recommends "increase(d) efforts to speed the translation of basic research into clinical applications" and "review of the reasonable pricing clause in relation to CRADAS, as they impact of the flow of industrial funds into clinical research and, thus, affect collaborations." Cancer Letter, March 25, 1994.

APPENDIX III.—TECHNOLOGY TRANSFER ACTIVITIES: FISCAL YEAR 1993—FISCAL YEAR 1998 [18]

[Dollars in thousands]

Activity	Fiscal years—					
	1993	1994	1995	1996	1997	1998
Invention Disclosures	232	259	271	196	268	287
Issued Patents	103	103	100	127	152	171
Executed Licenses	75	125	160	184	208	215
Royalties	$13,494	$18,487	$19,388	$26,995	$35,692	$39,563
Executed CRADAs	41	31	32	87	153	166

[18] On the web site of the National Institutes of Health (www.nih.gov/od/ott/nih93–98.htm)

APPENDIX IV: PRINCIPAL TECHNOLOGY TRANSFER MECHANISMS

Cooperative Research And Development Agreement (CRADA).—A CRADA is an agreement through which researchers at the NIH and private companies negotiate terms for cooperative research and define the rights of the parties to use licenses for any patents which might be created as a result of the research. CRADAs are the cornerstone of the basic research partnerships between the NIH and the biotechnology and pharmaceutical industries. In many cases the corporate partner pro-

vides funding and other resources to conduct research at the NIH. This corporate partner will then take the new technology and develop a marketable product. (The figures in the chart on page 10 in Appendix III shows a direct relationship between increases in NIH funding and increases in both CRADAs executed and license income generated.) In fiscal year 1996 and fiscal year 1997 the number of CRADAs increased dramatically. This increase in CRADA activity also led to increases in patents issued to companies which, in turn, will likely lead to the approval of new drugs in the market place.

Bayh-Dole Agreements.—A Bayh-Dole Agreement is the corollary to the CRADA for NIH grantees (universities and research institutions). Bayh-Dole Agreements are agreements between grantees and biopharmaceutical companies in which the parties define the licensing rights to patents that might be created and agree on how to share funds, materials, and scientists in the collaborative research effort. Bayh-Dole Agreements, like CRADAs, generate patent licensing income.

Licensing of Patents.—These partnerships focus on the licensing of patents on basic biomedical research discoveries. These licenses are critical to the relationship between biopharmaceutical companies and NIH and its grantees. Without patents to protect the taking of an invention by a competitor, a company cannot justify its research investment. It is crucial that NIH and its grantees, therefore, secure patents on their inventions so companies that invest money to develop inventions can benefit from their investment. The licensing of a patent require companies to make royalty payments to the proprietary owner of the license (or licensor) based on any sales of products attributed to the licensed patent.

The biotechnology industry expects to pay royalties as a part of a license agreement. Companies frequently license technology from one another, and the norm is to include royalty payments. It is important for NIH and its grantees to set royalty payment that are competitive with those that a company would expect to pay another company. Otherwise, companies would tend to seek technology from sources other than NIH or its grantees. The government has a reasonable expectation that its investment in research will be rewarded with royalty payments. No company would expect the government or its grantees to license technology without receiving a return on its investment. This return, in the form of royalty payments, can be used by the government to fund additional research.

Small Business Innovative Research (SBIR) & Small Business Technology Transfer (STTR) programs.—The SBIR and STTR programs—supported by federal government funding through NIH—provide funding to biopharmaceutical companies to conduct research and development of new or improved technologies that have the potential to succeed as commercial products. For 1998 the total estimated funding for SBIR and STTR programs combined was $280.6 million. These two programs are indispensable to the biotechnology industry as a source of seed capital for early stage biotechnology companies. BIO supports these programs and has worked with the NIH to provide recommendations on how to improve these programs and to assist in outreach to the biotechnology community. For specific funding levels for the SBIR and STTR programs see the chart on page eight

SUMMARY OF NIH SBIR AND STTR ACTIVITIES FISCAL YEAR 1993—FISCAL YEAR 1997 [19]

[Dollars in millions]

	Fiscal years—				
	1993	1994	1995	1996	1997
STTRs (awards)	NA	48	90	109	111
STTRs	NA	$4.7	$8.7	$13.9	$14.7
SBIRs (awards)	1,011	943	1,038	967	1,251
SBIRs	$121	$128.7	$175.1	$184.9	$246.2

[19] Contact Sonny Kreitman, Special Programs Officer, Office of Extramural Programs, National Institutes of Health ph: (301) 435–2688.

PREPARED STATEMENT OF HON. PAULA M. DELANEY, MAYOR, GAINESVILLE, FL

Mr. Chairman: On behalf of the City of Gainesville, Florida, I appreciate the opportunity to present this written testimony to you today. The City of Gainesville is seeking federal funds in the fiscal year 2000 Labor, Health and Human Services, Education and Related Agencies Appropriations bill for an advanced body-worn computer system for the field paramedic to use in patient care, decision-support, communications and record keeping. The impact for the entire region is considerable, since this county serves as the regional center for much of rural north Florida's

medical care, disaster management, and criminal justice services. The estimated cost of the system is $1,000,000, to be spread out over the three years it will take to complete the project.

The provision of emergency medical services has been highly developed over the past two decades through research and assistance from the federal government. Through these developments there are many advanced life support systems in place, which are staffed with paramedics. The paramedics operate at the front line of every type of emergency in which people are at risk. These include vehicle accidents, fires, chemical hazards, explosions, and terrorist events, up to and including weapons of mass destruction (WMD). The complexity of knowledge required of paramedics to perform effectively in this wide variety of circumstances continues to rise exponentially. Yet, throughout the federal government there are tools being developed which have immediate application to overcome the complexity facing the modern emergency medical system. What is needed is an integration of hardware, information technology, decision-support programming and advanced communications technology to support the paramedic in this wide variety of lifesaving interventions. Although there are various components of this project in development for other purposes, there is no known research that would provide a similar system with national application to emergency field services. There will be applications of this system for a number of national priorities, including anti-terrorist operations, trauma treatment, and enhanced rural medical care.

Paramedics in the field normally operate under direction of physicians at the emergency department. Caring for critical patients requires attempting to communicate a true picture of events to the physician. The paramedic must currently rely on a remote physician who is receiving limited information, to make an appropriate diagnosis and provide the correct treatment protocol. Yet, within the literature of emergency medicine there are hundreds of algorithms, akin to artificial intelligence, designed to correctly diagnose when complete information is provided in a specific sequence. These heuristic decision-support algorithms are complex and interact with each other. Computers are the only effective means to integrate the many complexities these interactions produce.

Computers could be used with great success in the field except for two primary shortcomings:

First of these is that the paramedic literally has his or her hands full with providing emergency care. (S)he cannot stop administering lifesaving care to enter data into a computer with a conventional keyboard, nor is the physician who is contacted by radio likely to either ask the questions in proper sequence or use the computer systems to furnish proper instructions. Handling hardware demands of a computer in this environment; outside, in all weather conditions, with poor lighting and dynamic events occurring, simply adds too much complexity to using this vital tool. Fortunately there have been recent developments in wearable computers. These are lightweight modules designed to fit in a belt-worn pack, which are then connected to a headset which has an eyepiece video display (which can also be equipped with a forward-looking video camera to record the wearer's eye view). The other components of the headpiece are a throat voice-activated microphone and earphone that allow two-way voice communication either with the computer or a radio system.

The second shortcoming is similar. Until recently there have not been speech recognition systems that could reliably accept voice input for decision-support or recording of vital information. Today, however, there are several inexpensive speech-to-text and text-to-speech engines for computers, which enabling direct communication with databases and artificial intelligence (AI) systems.

For the paramedic there is no transcriptionist. All records have to be reconstructed after the fact, from memory or from incomplete remote records from dispatcher reports and third parties. Sometimes a patient may be under the care of more than one service provider may. This can happen when a rural facility initiates care and the patient must be treated by first responders, followed by advanced providers and finally moved to a higher care level by a third caregiver, such as a helicopter flight crew. In this environment, the continuity of care may be maintained, but the records often become scattered, never reaching the final link in the chain. Incomplete or fragmented records mar most research into what works effectively in the field with paramedics. The use of a wearable computer, which is voice-activated, provides the ideal mechanism to review individual patient care to improve treatment proficiency, quality and training. The addition of a video cameral to that recording provides, literally, the complete picture.

There is the another problem for emergency care systems, probably the most difficult to solve and most in need of solution. When confronted with ambiguous data, indicative of a number of patient conditions, the paramedic must rapidly gather and sort volumes of information, develop a treatment plan and, with guidance from a

physician, attempt to restore stability. There are certain situations that are high criticality and low frequency. This means that the paramedic is unlikely to see the condition often, so it is unfamiliar. Simultaneously, the patient condition requires immediate and effective treatment for a survivable outcome. A few of these events include toxic exposures, multiple system trauma, complex rescue situations, and any other accidental or intentional event which leads to rare but lethal injuries.

This is a request for $1,000,000 in project development money to demonstrate a wearable computer system for field medical personnel. It will integrate available civilian and military technologies. Its goal is effective information management, field diagnosis—especially for rare and complex disorders such as chemical toxin exposures or biohazard exposures—and finally a real-time record of the events. This prototype will provide the model for expert systems to be placed in every field medical environment in the nation. In rural regions it will provide access to the sophisticated support of trauma centers and specialty physicians. In the urban environment it will simplify and improve proper management of mass casualty events. These may be rare, but they require high readiness and complex handling. Such events could include biological terrorism, chemical weapons, or even significant accidental exposures to these agents. They also include medically challenging cases such as thermal burns, poison exposures, and quick-acting illnesses, which threaten vital organ systems. The federal government has already funded the research that created the technologies to be used. There are military educational applications of this technology in use for aircraft maintenance. There are other applications in commercial development for inventory and maintenance applications, which are primarily data gathering or information recall systems. There have not been applications to the field practice of emergency medical care—a discipline that can produce an impressive return on development funding.

The Gainesville Fire Rescue Department (GFRD) is the primary applicant. The department is a Florida licensed advanced life-support (ALS) provider for the municipality of Gainesville and a wide urban area surrounding the city. The total population served is approximately 145,000 with an annual emergency call load of 20,000 emergency incidents, 15,000 of which are for emergency medical services (EMS). The department has a Regional Hazardous Materials Response Team providing training and emergency response to an eleven county area of North Florida. Except for its home county of Alachua, these counties are primarily rural with limited critical incident response capability. In addition, the department provides direct medical response services for the Gainesville Police Department's Special Response Team and the Alachua County Sheriff's Special Weapons and Tactics Team (SWAT). Paramedics who have completed the Department of Defense CONTOMS course are utilized in this role for support of high risk warrants and arrests, along with hostage or explosive device crises.

The project will be a partnership with a research team from the University of Florida's Shands Teaching Hospital, Department of Anesthesiology. The project consists of hardware (wearable computer, micro-video camera, digital radio interface); and software (speech-to-text, text-to-speech, heuristic decision support). These will be integrated into a body ensemble to be worn by field paramedics. Current medical and operational plans will be programmed into the computer to begin experiments with field use. This is a demonstration project to produce one limited use version of the device for continued experimental development. Results of the work will be shared as published research papers in medical journals, federal technology sharing publications, and journals common to emergency service providers.

This system is expected to greatly enhance the quality of treatment for critical trauma patients, mass casualties from all causes, including exposures to biological or chemical weapons, and complex medical illnesses. The potential for development of future uses is immense, following demonstration of successful integration. The benefits will be of national significance by making available a developed system that can be replicated at reasonable cost. It will create a standard platform for innovation and development among other users. The development team will make use of existing civilian and military technologies wherever possible.

The project will be divided into four phases. Phase one will involve research into existing technologies and development of a specification. Phase one will last 6 months and culminate in a document containing a detailed specification of the device to be developed and tested. Phase two will be development of a prototype system. Phase two will last 18 months. Phase three will be implementation and testing of the prototype and will last 9 months. Phase four will involve preparation of a final report and recommendations for further development and integration into EMS. It is quite possible that industry partners or further Federal funding will be obtained prior to completion of the project and that further development can continue uninterrupted.

The total cost of $1,000,000 will be spread over a three-year period, as follows:
Year 1—$338,000,
Year 2—$332,120, and
Year 3—$329,880.
The results (deliverables) will be:
—A prototype handheld or wearable computer with heads up display (HUD) with additional components containing communications software and capable of gathering vital signs information from monitoring devices, and/or controlling therapeutic devices.
—Medical algorithms for treating a variety of life threatening conditions and an advisory system as part of a user friendly intuitive interactive display with therapeutic options.
—Systems to bi-directionally communicate medical information and allow medical command to and from a remote location.
—The system will be evaluated in actual emergency events and the results published in research journals along with emergency medical magazines.

Thank you for the opportunity of presenting a unique opportunity for the design of a nationally significant tool for crisis intervention and successful lifesaving care. In fact, this innovation will have international impact as its full potential is realized.

PREPARED STATEMENT OF ROBERT M. CAREY, DEAN AND JAMES CARROLL FLIPPIN PROFESSOR OF MEDICAL SCIENCE, UNIVERSITY OF VIRGINIA SCHOOL OF MEDICINE, CHARLOTTESVILLE, VA

Mr. Chairman, I am pleased to present testimony on behalf of the University of Virginia in Charlottesville, Virginia, and its School of Medicine of which I am privileged to be Dean. The School of Medicine is one of the nation's best centers of medicine and biomedical investigation attracting over $60 million per year of NIH funds. During the decade of the 90's, three Albert Lasker Awards and two Nobel Prizes have been received on the basis of biomedical science performed at the University of Virginia. Four of our basic science departments in the School of Medicine are ranked in the top ten. Our vision is to be a leader in the discovery, dissemination and application of knowledge that will optimize the health of our citizens.

NIH funding has been absolutely critical in the achievement of our vision. For example, our renowned program in prostate cancer research, which is in the process of implementing gene therapy to prevent metastatic spread of the disease that kills, would not be possible without our National Cancer Institute Clinical Cancer Center, two large NIH program project grants, several individual NIH RO1-type research grants and the NIH General Clinical Research Center. Because all of these components are present in one institution, a working partnership has been created between basic scientists, translational researchers and patient-oriented clinical investigators. All of these parts are necessary to create an investigative environment that results in high impact.

At the University of Virginia School of Medicine, three major discoveries leading to the earlier-mentioned prizes in this decade were highly dependent on NIH funding: the discovery of G-proteins as a major mechanism whereby cells convert external signals into function, the discovery of nitric oxide as a major dilator of blood vessels and the discovery that peptic ulcer disease is due to a bacterium, Helicobacter pylori, treatable with a combination of antibiotics. Indeed, every advance in medical science requires two kinds of NIH support: infrastructure funding to provide the appropriate environment and program funding to conduct the research itself. While the need for program funds is self-evident, infrastructure support, which is equally important, is often overlooked.

Infrastructure support for biomedical science is at a crossroads today. Too little attention has been given especially to our research facilities in universities, which have not kept up with modern technology and many of which are woefully outdated. At the University of Virginia School of Medicine, for example, only one-third of our research space has been judged as excellent. One-third is adequate and one-third, which is 30 to 50 years old, is not capable of sustaining a modern biomedical research program. Almost all other medical school deans could tell you a similar story.

The problem of quality of research space is compounded by rapid and unanticipated advances in biomedical technology. Only a few years ago, the technique of homologous recombination in genetics opened the door to genetically engineered mice. This marvelous approach now allows us to eliminate a gene from an animal to observe the consequences of its removal. This is a powerful tool in determining the function of proteins encoded by a gene, thus realizing the benefits of the Human

Genome Project. These so-called "knockout mice" are adding much to our understanding of human biology and disease. Studies using these animals also form the basis for gene therapy. However, breeding these mice requires thousands of animals, which must be housed in a viral pathogen-free environment. Infection can result in loss of one, two or more years of work. The infrastructure at almost all universities, including our own, is insufficient to provide barrier facilities to house these valuable animals. This is posing a problem of crisis proportions in medical schools and other biological laboratories around the country.

Support for infrastructure through the NIH will enhance institutional research capacity by renovating outdated facilities and building new ones, creating new approaches to the support of animal facilities, providing state-of-the-art instrumentation and other research equipment and promoting information and computer technology. Infrastructure support can be provided by increasing funding to the National Center for Research Resources, the research support arm of the NIH.

Medical innovation and its successful implementation depend upon both the funding of promising areas of research and giving researchers access to modern laboratory facilities and equipment. As Dean of one of the nation's outstanding medical schools at the University of Virginia, I believe we need both to create a high level of stable research program funding and to establish an equitable policy for financing the construction, renovation and modernization of our biomedical research facilities. Thank you.

PREPARED STATEMENT OF DR. MICHAEL J. NOVACEK, PH.D., SENIOR VICE PRESIDENT AND PROVOST, AMERICAN MUSEUM OF NATURAL HISTORY

Thank you Mr. Chairman for allowing me to submit testimony on behalf of the American Museum of Natural History to the Subcommittee today.

ABOUT THE AMERICAN MUSEUM OF NATURAL HISTORY

Founded in 1869, the American Museum of Natural History is one of the nation's pre-eminent scientific and educational institutions. For over 129 years, the Museum has pursued a mission of examining critical scientific issues and increasing public knowledge about them. Throughout the Museum's history, its explorers and scientists have pioneered discoveries that have offered us new ways of looking at nature and human civilization. The Museum has sponsored thousands of expeditions, sending scientists and explorers to every continent. This rich scientific legacy includes an irreplaceable record of life on earth in collections of some 32 million natural specimens and cultural artifacts that are an extraordinary research tool and represent the focus of science at the Museum. The Museum's power to interpret wide-ranging scientific discoveries and convey them imaginatively has inspired generations of visitors to its grand exhibition halls and educated millions about the marvels of the natural world and the vitality of human culture. With four million visitors annually (of whom half are schoolchildren), and a staff of dedicated educators who seek to inspire curiosity and a desire to learn in both children and adults, the Museum is known as one of the nation's preeminent scientific and educational institutions.

More than 200 active research scientists with internationally recognized expertise conduct more than 150 field projects each year. Museum scientists in the ten scientific departments are retracing the evolutionary tree, documenting changes in the environment, and describing the achievements of human culture—affecting the public's understanding of where we come from and where we may be headed.

The Museum's ongoing research provides the foundation for its educational mission. The goals of its educational programs include increasing scientific literacy among both adults and children nationwide, addressing issues that affect our daily lives and the future of the planet and its inhabitants, and providing a forum for exploring world cultures. The recent Museum's launching of the National Center for Science Literacy, Education, and Technology in partnership with NASA helps to further these goals. In creating the National Center, the Museum and NASA recognized an opportunity to combine and leverage their incomparable resources. The National Center creates materials and programs that reach beyond our institutional walls into homes, schools, museums, and community organizations around the nation.

The Museum actively continues a tradition of creating some of the greatest scientific exhibitions in the world. Early in the year 2000, the Museum will open the new Rose Center for Earth and Space, in one of the most exciting chapters in the Museum's long and distinguished history of science and education. The Rose Center includes a newly rebuilt and updated Hayden Planetarium that will allow visitors

to journey among the stars and planets in our own galaxy as well as those of other galaxies; the Lewis B. and Dorothy Cullman Hall of the Universe, where interactive technology and participatory displays will elucidate important principles of astronomy and astrophysics; and the adjoining Gottesman Hall of Planet Earth (opening in 1999). In exploring the processes that determine how Earth works, the Hall will contain an array of fascinating natural samples that will include, among others, an ice core from Greenland that contains in its strata evidence of climatic shifts that occurred thousands of years ago and a massive fold of rock hewn from a quarry. Also on display will be the first-ever retrieved "black smokers" (chimney-like sulfide structures that grow at hydrothermal vents in the deep ocean), recovered this summer by Museum scientists and colleagues from the University of Washington with important support from NASA. The Rose Center for Earth and Space will enable the Museum to join science and education to provide a seamless educational journey taking visitors from the beginnings of the universe, to the formation and processes of Earth to the extraordinary and irreplaceable diversity of life and cultures on our planet.

SUPPORT FOR THE NATIONAL INSTITUTE OF HEALTH

While not a traditional health institution, the Museum supports a tremendous amount of valuable research and educational programs that complement the goals of NIH.

The Museum is currently showing a temporary exhibition entitled, "Epidemic! The World of Infectious Disease." The exhibition examines in detail the natural history of disease from biological and cultural vantage points. In emphasizing the delicate balance among microorganisms, humans, and other animals, and the environments in which they live, the exhibition underscores the importance of understanding the global nature of disease. Specific diseases, such as malaria, AIDS, and tuberculosis are used as examples to illustrate larger issues. Extensive educational programming including films, lectures, and a special children's "Infection, Detection, Protection" workbook accompany this exhibition.

The Museum's research also supports the goals of NIH. With the advent of DNA sequencing, museum collections have become critical baseline resources for the assessment of the genetic diversity of natural populations. Genomes, especially those of the simplest organisms, provide a window onto the fundamental mechanics of life. Studying the DNA of nonhuman organisms, the sponsors of the research say, can lead to an understanding of their natural capabilities that can be applied toward solving challenges in health care. We believe that the Museum's accomplishments in this area support and complement the National Institute of Health's goals.

The American Museum has a history of being at the forefront of conservation activities. In addition, the molecular systematics programs at the Museum are on the cutting edge in the use of DNA sequences in conservation and evolutionary research. The Museum houses two molecular laboratories that are directed by four curators from the Museum and one from The New York Botanical Garden. Current studies focus on a variety of endangered species representing diverse geographic and taxonomic scope, including: tiger beetles and moths of the Atlantic coast of North America, sturgeon of the Caspian Sea, muntjacs (small deer) recently discovered in Southeast Asia, lemurs and whales of Madagascar, spotted owls of the Pacific Northwest, tiger populations throughout Asia, and right whales around the world. Ancient DNA, essential for historical study of changes in genetic markers in endangered species, has been recovered from museum specimens of rare or extinct animals, as well as 25-million-year-old termites fossilized in amber.

As more species become threatened and extinct, it is more critical than ever to catalogue and store the variety of life's natural genetic diversity so that it will be available far into the future. For these reasons, the Museum has launched a new effort to create a super-cold storage facility. Located in a new, state-of-the-art collections and laboratory building, this new storage facility will enable Museum scientists and researchers from around the world to perform unique and vital DNA research. Molecular techniques have revolutionized the study of biology, including conservation, evolution, and medicine. As part of our ongoing mission in collections-based research we propose expanding activities in the preservation of biological tissues and molecular libraries in super-cold storage for current and future genetic research.

Better understanding of the natural arrangements of genomes and interactions among genes is driving, and will continue to drive, the development of novel therapies for disease. It is also clear that many genes of significant scientific and medical importance are found only in a few organisms. Such natural products are useful in ways we are only beginning to understand. Tissue collections such as the one we

propose expanding at the Museum will preserve genetic material and gene products from rare and endangered organisms that may go extinct before science fully exploits their potential.

Now in operation for eight years, the Museum's molecular laboratories have accrued tens of thousands of specimens. In the near future we plan to create a database not only for record keeping, but also to make this collection easily searched via the Internet and accessible for loans by scientists outside the Museum, including health researchers. We foresee increased loan activity as the fields of molecular systematics and comparative genomics continue to grow. Because tissues could be easily depleted by several requests, molecular libraries (DNA in fragments multiplied and stored in easily workable vectors) are or will be constructed for many of these specimens. Many of the tissues and molecular libraries in the Museum's frozen collection come from long-term field projects with extensively detailed data.

Molecular information is important for understanding the history of life. In the past, the time and expense of DNA sequencing forced systematists to collect sequences from only one gene per species. A single set of character information is inadequate to represent the complexity of the organisms and their history. Fortunately, DNA sequencing technology has improved rapidly in the past five years (bases sequenced per unit time has increased at least tenfold). This improvement has allowed the Museum's molecular labs to address gaps in knowledge of biodiversity by sequencing DNA from rare, endangered, and understudied organisms. Concomitantly, Museum scientists are working to improve the theory and implementation of phylogenetic analysis of vast data sets of DNA sequences and other forms of biological information such as the anatomy of extant and extinct organisms. Sequence data are shared worldwide on NIH's Genbank database and via original scientific research disseminated in theses and peer reviewed publications.

MUSEUM COLLECTIONS AND LIBRARY

The collections of the American Museum of Natural History are considered to be the largest non-federal Museum collection in America, and one of the largest and most significant biological collections in the world. The collections are organized around the departments of Entomology, Herpetology, Ichthyology, Invertebrates, Mammalogy, Ornithology, and Vertebrate Paleontology, and often include endangered and extinct species as well as many of the only known "type specimens" or examples of species by which all other finds are compared. The Museum's 32 million specimens and artifacts, collected over 129 years from the far corners of the earth, are all located on-site to allow ease of access to scientists. Collections like those of the Museum are historical libraries of expertly identified examples of species and artifacts, associated with data about when and where they were collected. Such collections provide essential baseline data for Museum scientists as well as more than 250 national and international visiting scientists each year.

Collections of the diversity of the natural world are the basis for the interrelated missions of the Museum: research, education, and exhibition. The Museum is similar to a research university with a faculty of 42 curators from diverse fields such anthropology, earth and planetary sciences, and all branches of zoology. Yet the Museum is distinct in the sense that the Museum's mission extends beyond research and teaching. Museum curators are active research scientists, exhibition advisors, and caretakers of ever growing collections of cultural artifacts and biological and geological specimens.

The Museum is home to the largest unified natural history library in the Western Hemisphere. The collection is an important resource for students from the several dozen colleges and universities located in New York City and in the tri-state area, as well as researchers visiting from the far corners of the globe. The collection contains over 485,000 volumes, including books, journals, rare documents, photos, several hundred films, over one million photographic images, and is rich in retrospective materials, some dating to the 15th century.

Highlights of the Library's collection include over 300 manuscript collections of notable naturalists and scientists; a unique collection of 13,000 rare books that spans over 500 years of scientific and expedition literature; and diaries and logs including Captain James Cook's account of Australia (1783), and Charles Darwin's Zoology of the voyage of "H.M.S. Beagle" (1839–43) which narrate and illustrate voyagers of exploration and discovery to new lands and habitats. New publications and current issues of journals are added to the library on an ongoing basis.

The Museum's halls of vertebrate evolution provide an excellent example of the relationship between scientific collections and exhibition. In these halls, visitors walk directly along a phylogenetic tree indicated by a pathway on the floor. At each branch in the tree a visitor can stop and view fossils that exemplify sets of anatom-

ical features that inform scientists about natural groups of organisms. The collections are also the source of the extraordinary "Spectrum of Life" exhibit in the new Hall of Biodiversity which includes more than a thousand expertly mounted specimens from 28 scientific classifications and is perhaps the worlds most comprehensive display of the diversity of life and its evolution. It includes interactive computer kiosks that visitors use to identify and interrelate organisms on evolutionary trees. The confluence of collections, evolutionary research, and beautiful exhibition makes these halls among most compelling educational features of the Museum.

The Museum's Anthropology Department is nearing the end of a two decade collection storage upgrade and digitization project which was supported by the National Endowment for the Humanities and undertaken in order to allow more scholars greater access to these vital and magnificent collections. The new digital image database and accompanying electronic catalog allows the Museum to provide staff, visiting scholars, and off-site researchers with much-needed, easier accessibility. The storage facility upgrade, scheduled to be complete in 2002, will ensure that the artifacts are protected and stored for the study of generations to come.

BIOLOGICAL COLLECTION STORAGE UPGRADE AND DIGITIZATION PROJECT

With the successful anthropology storage upgrade and digitization project nearly complete, the Museum now turns its focus towards upgrading storage facilities and digitizing the biological collections for better preservation and improved data access. The Institute of Museum and Library Sciences has a distinguished history of supporting cutting edge collection and technological practices. We seek a partnership with IMLS that will allow us to be in the forefront of collection practices and a model for the nation.

Technological innovation for greater public access

Biological science at the Museum centers on expert documentation of species and investigation of their evolutionary and ecological relationships. We seek support in fiscal year 2000 for our ongoing efforts to develop and expand model digitization initiatives so that we may share our collections with a broader audience while protecting the integrity of the objects for years to come. The digital imaging and electronic cataloging of many of the Museum's collections, coupled with the technological improvements in the Museum's education infrastructure, will allow the Museum to reach the new goal of sharing our library of objects with a national audience. For the first time, researchers across the nation and around the world will be able to easily access this valuable information.

Due to the unparalleled interest in the Museum's collections and unwieldiness of the specimens a digital data base would be of great scientific and public interest. We propose a digital data base to allow digitized specimens and field data to be searched across many fields (for instance by locality or age). Detailed digital renderings would allow ready and safe access to often fragile archival material, and allow off-site workers to peruse the collection and strategically plan visits to the Museum. These last two matters are key. If a researcher can plan a visit with the help of the database the productivity of their visit to the Museum's collections will be significantly enhanced. We propose to develop a web front end to the digital database which will therefore make it available worldwide to those interested in natural history.

In addition, the Museum plans a significant model digitization project for resources located in our natural history library. Support from IMLS will allow the Museum Library to collaborate with the scientific departments to create a valuable digital resource for students and scientists across the nation.

Collection storage facilities upgrade

We seek support in fiscal year 2000 for our ongoing efforts to upgrade our collection storage facilities, many of which were built early this century. The Museum's collections are the heart and soul of our scientific research, permanent and temporary exhibitions as well as our education programs. The collections allow undergraduate, graduate, and post-graduate students, and even high-school students to conduct real research projects in intensive learning programs. Access to the Museum's collections is central to the work not only of Museum scientists but of scientists from around the world. As the collections grow, questions about how to curate them, including the issue of limited physical storage space, arise. While many similar institutions house their collections separately from their faculty, the Museum is committed to keeping its scientists, educators and collections together by expanding on site. In fiscal year 1998 we began construction on a new collections and research facility, the Natural Sciences Building, within the space enclosed by the 23 interconnected structures that form the Museum. The building will hold a substantial

amount of new compact storage including a unique super-cold storage facility to allow for the preservation and future study of DNA, goals which can not be attained through traditional storage methods. We seek the partnership of IMLS for new storage equipment in the new Natural Sciences Building as well as other collection areas in the Museum.

The American Museum of Natural History seeks $1,000,000 in support for critical upgrades to unique and vital specimen and library collection storage facilities, and to develop and expand model digitization initiatives.

PREPARED STATEMENT OF CYRUS M. JOLLIVETTE, VICE PRESIDENT FOR GOVERNMENT RELATIONS

Mr. Chairman and Members of the Subcommittee: I appreciate the opportunity to submit this statement for the record on behalf of the University of Miami in Coral Gables, Florida. The University is seeking your support for several important initiatives, all of which will provide great benefit for Florida and the nation.

Founded in 1925, the University of Miami is the largest, most comprehensive private research university in the southeastern United States.

With its main campus located in the suburban City of Coral Gables, the University of Miami currently enrolls 13,422 undergraduate and graduate students from all 50 states and 148 foreign countries. The University offers 110 undergraduate programs, 95 master's programs, 55 doctoral programs and two professional areas of study through its 14 schools and colleges. Students can choose from the following fields of study: architecture, arts and sciences, business, communication, continuing studies, education, engineering, international studies, law, marine and atmospheric sciences, medicine, music, and nursing. Of the 1,865 full-time faculty members more than 97 percent hold a Ph.D. or terminal degree in their field. At its medical campus near downtown Miami, the University of Miami is best known for research in AIDS, cancer, diabetes, eye diseases, and spinal cord injury. The Rosenstiel School of Marine and Atmospheric Science on Virginia Key is one of the top three marine science schools in the nation.

First, we seek your endorsement of our Joint Center for Pediatric Asthma and Respiratory Disease, at the University's Rosenstiel School of Marine and Atmospheric Sciences and the School of Medicine. Our objective is to establish a center for the Southern United States to conduct, promote, and support research into the effects of ambient particulate matter (PM) and other airborne constituents on human health to formulate future environmental regulations with a strong scientific foundation. University of Miami

The Center will focus on airborne-particle/health issues in the southeastern United States—a region that is subjected to a wide range of airborne pollutant impacts. The levels of ozone and oxidants are seasonably very high over large regions and the rate of noncompliance with the ozone standards is increasing, resulting in a number of large-scale, atmospheric, chemistry/pollution studies. Populations in coastal regions are impacted by other types of particles whose health-related properties have not been well characterized or understood, including the impact of windblown sea-salt; marine toxins, bacteria, and various marine micro-organisms. The Center will also provide expertise on matters relating to air quality and human health in the Southeastern U.S.

My scientific and medical colleagues have defined seven specific objectives of the proposed research that will test the hypothesis that exposure to ambient (indoor and outdoor) PM significantly affects the cardiopulmonary response of susceptible populations of children and seniors. They will provide a broad-base of expertise in atmospheric chemistry (indoor and outdoor), exposure assessment, cardiopulmonary medicine, epidemiology, and public health.

For fiscal year 2000, we respectfully request that you direct the National Institutes of Health to establish a research effort of this type based in southeast Florida for this important scientific and medical initiative.

Next, Mr. Chairman, we seek your support of the Clinical Diabetes Islet Transplant initiative at the University's Diabetes Research Institute. The National Institutes of Health has announced a ground breaking clinical research initiative focused on Type 1 diabetes and one of its associated complications, kidney disease. The objective is to establish tolerance to transplanted tissue and cure diabetes by islet cell transplantation. The University of Miami Diabetes Research Institute will be the only non-government partner in this historic partnership, along with the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), the Naval Medical Research Center, and the Walter Reed Army Medical Center (WRAMC).

This coveted NIH recognition is based on the DRIs achievements and commitment to islet transplant technology. During the past year, the DRI and the Naval Medical Research Center have obtained sufficient and compelling data from non-human primate experiments using highly promising monoclonal antibodies. These results have created great enthusiasm throughout the scientific community putting the DRI-Navy team literally months, if not years ahead of other centers in the search for a cure for diabetes.

Responding to pressure from patient advocates and lobbying groups, together with increasing successes in pre-clinical research, the NIH has found itself obliged to address its lack of a clinical islet transplant program. It has, therefore, entered the islet transplantation arena via a new Navy-NIDDK Transplantation and Autoimmunity Research Branch. Of all existing diabetes centers, the University of Miami Diabetes Research Institute has been selected to help translate current research advances from the laboratory into pilot clinical trials in patients with Type 1 diabetes.

For the DRI, the partnership represents an unprecedented opportunity to couple its unique and sought-after expertise with the vast resources of the federal government. It will provide the DRI with access to previously exclusive core facilities and limited antibodies to accelerate research. DRI will be able to make full use of its experience in both pre-clinical testing of the latest antibodies, and in the development of clinical research protocols aimed at establishing tolerance to transplanted tissues. The DRI will provide the NIH with islet isolation equipment and train their team.

The NIH will utilize intramural funds to renovate one of its research hospitals, recruit necessary personnel, and acquire equipment and supplies for clinical trials for which the Diabetes Research Institute is not eligible. To date, private support provided all funding for the studies that led to this unique private-public partnership and will continue to bridge the funding gaps.

The University of Miami Diabetes Research Institute is seeking to leverage private support and new federal support to enable it to take advantage of this historic opportunity which will contribute directly to finding a cure for diabetes.

This new clinical transplant initiative will require new and renovated laboratories which must receive FDA validation prior to use in human trials. For fiscal year 2000, the Diabetes Research Institute seeks the Subcommittee's support to allocate $3 million in the NIH extramural facilities account for the renovation and construction of a Clinical Diabetes Islet Transplant Research facility for the Diabetes Research Institute in Miami, Florida.

Next, the University of Miami, its School of Medicine, the Sylvester Cancer Center, the Courtelis Center for Research and Treatment and the Batchelor Children's Center have developed a major cancer collaboration of special relevance to ethnically diverse and minority populations, our national military workforce, and children.

Cancer is the number two cause of death in America. It does not spare anyone based on their age, sex, ethnic background or socio-economic status. We know that basic research will eventually lead to the causes and hopefully cures for this dreaded disease. However, research has already given us tools for prevention and early detection that will reduce the suffering from cancer until cures can be found. The programs that we have listed as part of our initiative will apply these tools in a variety of settings for prevention, control, and treatment, especially in multi-ethnic, diverse, minority populations. This translational approach to biomedical research, that is, applying the basic scientific knowledge we have already gained to populations in clinical settings, is a key component of the research at the University of Miami. By applying this knowledge, we can reduce the morbidity, mortality, and improve the quality of life for all our citizens.

Florida is often called the "bellwether state" or "window to the future" for disease incidence. The state has been having a significant increase in some of the most common cancers among the minority populations including prostate and breast cancer. We are developing an ever-greater understanding of the potential and critically important areas of genetic differences, genetic susceptibility, genetic research and genetic epidemiology in developing effective cancer prevention and control programs. These cutting-edge research technologies also allow us to develop successful treatments for approaches to high-risk and at-risk populations.

Working with community-based research and intervention strategies, University of Miami scientists have developed a broad array of data on the attitudes of different minority populations toward cancer prevention, detection and treatment. An understanding of these populations places us in a unique position to apply the tools we have already developed to reduce cancer incidence. While the Sylvester Comprehensive Cancer Center has studies in many areas, there are major programs on early detection, treatment and prevention of prostate and breast cancer. These dis-

eases are highly unpredictable, but tend to occur at younger ages and to be more aggressive in minority populations.

We are seeking the allocation of $8.5 million for a Model Cancer Prevention and Control Program that is a collaborative effort of the Sylvester Cancer Center and the Courtelis Center which will utilize our focus and access to a nationally unique, unparalleled ethnically diverse, minority patient/population base to more fully and effectively develop, coordinate, and focus cancer prevention and control efforts. We are seeking to expand our concentrated clinical cancer research, treatment prevention and control strategies in five crucial areas: (1) early detection; (2) primary and secondary prevention research; (3) genetic epidemiology and research; (4) molecular epidemiology; and (5) expanded capacity of the research and treatment center. As a part of this collaboration, it is our intent to involve the Batchelor Children's Research Center to embrace its clinical capacity in pediatric bone marrow and cord blood transplantation. The Miami-based Batchelor Center is one of the nation's leading sites for this critical work. The final part of the collaboration provides for the enhancement of our Breast Cancer Early Detection Program to increase the number of women screened from an average of 15 per day to 50 per day, or a total of 12,500 women per year.

Next, Mr. Chairman, we seek your support for a joint University of Miami/Florida State University Florida project that would enhance research and research training in health and aging at Florida State University through a collaborative effort between faculty associated with the Pepper Institute on Aging and Public Policy and faculty associated with the Center on Adult Development and Aging at the University of Miami.

The goal will be achieved through the development of interdisciplinary program in Aging and Health Promotion that focuses on the multidimensional aspects of aging. The joint program will combine the social science strengths of Florida State University faculty and the biomedical and clinical strengths of the University of Miami. The program will help to increase the knowledge and interest of current faculty in health and aging issues, including both physical and mental health, and will support faculty in developing research skills applicable to the study of health and aging. The specific intent of the program is the expansion of research activities directed toward (1) disease prevention, (2) diagnosis and assessment of functional abilities, (3) intervention and development of strategies to compensate for age-related functional declines, (4) basic research on aging and health.

Finally, the University of Miami proposes to create a unique, multi-media resource of Cuban research and teaching materials to be known as "The Cuba Heritage Collection. "The Cuban Heritage Collection will be housed in an area specifically designed to permanently store, display and provide non-destructive access to the materials making up the Collection. The Cuban heritage Collection will cover all aspects of Cuban history and culture, especially as it is reflected in the United States, and will be based on the University's existing, large and valuable Cuban Collection.

In additional to the traditional access to the materials in the Cuban Heritage Collection, the University of Miami proposes to provide enriched indexing that will enable more efficient use of this information resource. The Collection will be accessible to off-campus scholars and students through the Internet and in published digital products.

The University is seeking $3.5 million from the Labor, HHS, and Education Appropriations Subcommittee through the Institute of Museum and Library Services to create, develop, and implement the Cuban Heritage Collection.

Mr. Chairman, we understand how difficult year this will be for you and the Subcommittee. However, we respectfully request that you give serious consideration to these vital initiatives, all of which have great implications and will provide exceptional benefits to the well-being of the nation.

PREPARED STATEMENT OF JOHN J. MCDONOUGH, CHAIRMAN OF THE BOARD, JDF INTERNATIONAL AND ALLISON MCDONOUGH, MEMBER, JDF LAY REVIEW COMMITTEE, JUVENILE DIABETES FOUNDATION INTERNATIONAL

JOHN MCDONOUGH. Mr. Chairman and Members of the Subcommittee, I am John J. McDonough, a husband, father, grandfather, volunteer advocate, and businessman. I am the Vice Chairman and CEO of Newell Rubbermaid Inc., and I'm pleased to be here today as the Chairman of the International Board of Directors of the Juvenile Diabetes Foundation.

I thank you and the other Members of the Subcommittee for your strong support of medical research over the years. Last year's 15-percent increase in NIH funding is moving us closer to a cure for diabetes and its complications. We are very much

looking forward to working with you again this year to try to secure another 15-percent increase so that every identified diabetes research opportunity can be fully funded.

My family strongly supports efforts to increase funding for medical research. Our desire to find a cure couldn't be greater. To date, our family has contributed $14.5 million dollars to JDF and will keep on giving until a cure is found.

My wife, Marilyn, lost two of her aunts to diabetes. My paternal grandfather died from the complications of diabetes in the 1920s. He was ravaged by this disease just at the time insulin was becoming available. I have had insulin-dependent diabetes for 56 years, and my daughter Allison has had insulin-dependent diabetes for 16 years. Marilyn and I have 4 other children and 4⅔ grandchildren, with more to come, we hope. And we don't want to see any more of this disease that cripples and kills so many people every year.

I remember the day I was diagnosed very clearly. I was in a large ward at a Chicago hospital, and my parents came in and told me I had something called diabetes. My father was simply devastated. He had married late, was then 50 years old, and it hadn't been that many years since he watched his father die from this disease. Thanks to my mother, I understood perfectly what I had to do. You see, she was a very modern lady, even 56 years ago. Like young parents today, she believed in time outs . . . the only difference being that her idea of a time out was 30 seconds to rest her arm before cracking me again with my father's razor strap!

From the time I was a child, I knew what I had to do to deal with this problem called diabetes, and I've done that all my life. There are probably few people who have worked harder at controlling my blood sugar levels than I have over a long period of time. Yet over 55,000 shots later, my experience makes the point that insulin is not a cure and it doesn't prevent complications. It is merely life support. Despite good genes and excellent medical care, I've not been able to avoid some complications of this terrible disease, including the amputation of my left leg last September.

We cannot become complacent. The research being done today is only a fraction of what needs to be done, and the relevant research that can be done today is limited only by the money available to fund it.

ALLISON MCDONOUGH. I was diagnosed with diabetes in 1983 at the age of 25. My parents were devastated. Emotionally, my father felt he was to blame, even though intellectually he knew he had no control over my diagnosis. And my mother, who had watched her aunts die from the disease, now had the same fears for me that she had had for my father for so many years.

When my father was diagnosed in 1943 at the age of six, he was told he would not live to be ten. At ten he was told he probably wouldn't live to be 20, and so on. He is fond of saying that he is not afraid of dying, but is afraid of not living. I, however, am afraid of both, and not just for myself but for my dad, and also the undiagnosed members of my family.

Living with diabetes, with all its injections, blood tests and insulin reactions is a cumbersome and difficult full-time job, and there is no such thing as remission. Yet it's the constant dread of wondering when diabetes will strike our family again that I hate more.

Last fall my father not only lost his leg, he almost lost his life. There was one week after the amputation in which his stump needed to be left open. Every day I forced myself to look into his open leg, searching for signs in his tissue that healing was taking place. He would cry and tell me not to look, and that it wouldn't happen to me. That hole in his leg has left a hole in my heart, and just as I forced myself to stare it down, I don't want my siblings or future generations of my family to ever have to stare down the truth about diabetes as we who live with it do. In my family I want this disease to end with me.

JOHN MCDONOUGH. Diabetes kills one person every three minutes and reduces life expectancy by 30 percent. The disease costs our nation $98 billion dollars annually and absorbs one of every five Medicare dollars. While we at JDF work hard to raise funds to support research that is leading us closer to a cure, we need your help.

As you know, the Diabetes Research Working Group established by your Subcommittee has issued a report, which includes a plan to attack the epidemic of diabetes and its complications. The report also contains a specific recommendation for the National Institutes of Health to provide $827 million dollars for diabetes research in fiscal year 2000, a level supported by JDF.

We seek your help in securing this funding so that every parent can tell every child with diabetes that everything possible is being done to find a cure. We speak for all of our fellow JDF volunteers—both children and adults who suffer from diabetes and/or work on behalf of their loved ones—when we say that only a cure will

suffice. Mr. Chairman, with continued support from you and the other Members of the Subcommittee, we will find that cure.

Thank you for this opportunity to testify.

PREPARED STATEMENT OF DR. JAMES CRAPO, CHAIRMAN, DEPARTMENT OF MEDICINE, NATIONAL JEWISH MEDICAL AND RESEARCH CENTER

Mr. Chairman and Members of the Subcommittee, thank you for your support last year and the opportunity to present this testimony regarding the National Jewish Medical and Research Center's proposal to build an integrated Center for Environmental Health Research and Service (CEHRS). This Center will, under one roof, support research and provide clinical services for patients with respiratory and immune diseases with the mission of controlling or eradicating environmental and occupational illness in the Rocky Mountain Region. It will serve as a regional resource and national model for the delivery of environmental clinical health services, conduct both basic and field research on environmental illness, and "translate" new knowledge, to better inform the public and help guide rational environmental policy by government, at both regional and national levels.

National Jewish Medical and Research Center is known worldwide for the diagnosis and treatment of patients with environmental, respiratory, immune and allergic disorders, and for groundbreaking medical research. For the past 20 years, this century-old nonsectarian, nonprofit medical center has earned an international reputation for its treatment of environmental illness and for research leading to the detection and prevention of environmental disorders including asthma, berylliosis, tuberculosis and building-related illnesses.

With funding from Federal agencies including the NIEHS, NHLBI, NIAID, EPA, DOE, and CDC/NIOSH, as well as foundations and private industry, National Jewish has become one of the leaders in the field of environmental health. National Jewish is deeply committed to providing accessible, affordable and high quality care for environmentally and occupationally-exposed individuals, to consulting for government and industries in the region and nationally, and to educating medical professionals and the public on matters of environmental risk and health.

Our nation faces a significant challenge for the 21st century—how to safeguard the health of the American public from environmental hazards. We are faced with the reality that many Americans, particularly the working poor, blue collar middle class, minorities, children and the elderly, are exposed daily to environmental toxins that may cause major lung, heart, immune and allergic diseases, disability and untimely death. We must find ways to better diagnose, treat and, most importantly, prevent environmental disease.

Today federal agencies and corporations face the daunting task of cleaning up environmental "sins of the past"—without unduly endangering the health of today's hazardous waste workers and the members of communities that surround them. The Colorado region inherited the environmental legacy dating back to the industrial revolution—large tracts of polluted land and buildings, including the former nuclear weapons plant at Rocky Flats and more than a dozen other sites of high contamination caused by past mining and other industry. While the state continues its efforts to clean up this toxic legacy little attention has been paid to addressing the environmental disease that has resulted from years of high levels of environmental contamination and pollution.

The State of Colorado has historically been medically underserved, in environmental health services, with fewer than 40 medical practitioners in Colorado who are board certified to practice environmental and occupational health. While the Division of Environmental and Occupational Health Sciences at National Jewish provides consultation to industry, agriculture, community groups, and labor, its services are outstripped by the regional need for expertise. National Jewish is forced to turn away many patients and groups who have environmental concerns because of physical and staffing limitations at the Center. These needs range from community groups seeking advice on the hazards of radioactivity and of metal-contaminated soil, to industries needing help in the control of lead poisoning and biological hazard exposures, to regional agencies seeking aid in the investigation of disease outbreaks caused by airborne molds or tuberculosis-like organisms.

National Jewish is uniquely positioned in the Rocky Mountain region to serve as such a model health care institution for implementing innovative environmental health programs that reduce the risk of respiratory and immune system disease.

Regionally and nationally, the diseases that are treated at National Jewish Medical and Research Center are on the rise, including asthma, diseases due to environmental tobacco smoke, building-related respiratory and allergic illnesses. National

Jewish Medical and Research Center specializes in helping both small and large regional employers address practical issues of toxic exposure assessment, exposure control, medical management of occupational illness, and remediation. Employees and their employers, while aiming to make the workplace safer and more productive, often lack enough information about the toxic effects of airborne chemicals, metals, and organic matter that produce disability. Recent studies show that 1 in 10-hospital admissions is related to a workplace injury or exposure. More than half of all patients seen in general medicine clinics in the central U.S. report past or ongoing exposure to one or more known toxin.

The solutions to these environmental health dilemmas are to prevent exposures from causing disease and, if environmental exposures have already occurred, to detect disease earlier and to develop more effective treatments for disease.

National Jewish can best increase our effectiveness by housing these major activities in a single, dedicated location. At this time, the activities, staff and leadership for environmental medicine and research are scattered across the three-block National Jewish Campus. The goal is to construct a building that will help to consolidate all environmental health research and services. The CEHRS will be a showcase for the application of the most advanced environmental science and directly to the prevention of disease in groups of Americans at environmental risk. By showing how a multidisciplinary approach can help eradicate environmental respiratory and allergic diseases, our Center will be a model for other centers around the country who may address other forms of environmental illness, such as those linked to skin disease, neurologic disorders, liver disease, and cancer. National Jewish Medical and Research Center believes that by maintaining a tight focus of both clinical care and research in an area of great need—the respiratory and immune systems—its Center will be able to deliver long term solutions to the most important forms of environmental disease.

The CEHRS will meet this need by integrating the following program components in the new Center:

The Clinic for Environmental and Occupational Health Care.—A combined adult and pediatric outpatient clinical practice staffed by experienced environmental and occupational health physicians and nurses who diagnose and treat environmental disorders. Annually, this clinical group screens and evaluates more than 2,000 patients with suspected environmental or occupational lung and allergic disorders.

The Environmental Disease Prevention and Research Service.—A multidisciplinary team of physicians, basic science researchers, epidemiologists, industrial hygienists, and health educators who work directly with individual patients to measure airborne exposures to toxins and who implement innovative programs that detect the effects of chemicals in individuals and in the air. This service conducts practical research aimed at "real life" problem solving. For example, this Unit develops and tests the effectiveness of medical surveillance programs in industry. The goal is to devise practical, cost-effective solutions to reducing risks of cancer, lung fibrosis, and allergic lung disease.

The Environmental Away-Team Consultation Service.—A mobile consultation service staffed by a team of environmental and occupational health experts who go anywhere in the country to measure environmental exposures, monitor for disease, and advise industrial and agricultural employers, labor, and private citizens on the management and control of environmental hazards. This service has gone on-site to more than 20 states.

The Respiratory Protection Program.—A mobile service that helps individuals and corporations to educate and provide appropriate types of masks for people being potentially exposed to airborne hazards. Firefighters, hazardous waste workers, municipal employees, and others who encounter potentially lethal exposures to highly toxic materials call on this service.

The Environmental Education/Community Ourteach Service.—A risk communication service that utilizes the internet as well as more traditional educational approaches to deliver up-to-date, balanced, practical environmental information to civic groups, labor, industry, and local and federal government agencies.

The Occupational and Environmental Medicine Training Program.—Based at National Jewish and the Department of Preventive Medicine and Biometrics at the University of Colorado School of Medicine, this is the only training program for environmental medicine in the state of Colorado.

The Environmental Toxicology Section.—A research unit dedicated to understanding oxidative stress—a process that occurs during the body's conversion of fuel to energy. This oxidative process produces disease when undesirable oxidant gases or dusts are inhaled, causing inflammation.

The Environmental Immunology Laboratory.—A research unit dedicated to understanding how environmental toxins, including metal dust and bioaerosols such as latex and bacteria, cause allergic diseases.

At this time, National Jewish is the only academic research facility in Colorado that provides clinical care for patients with suspected environmental or occupational illnesses. It is one of the only centers in the nation that is recognized for expertise in environmental and occupational lung and immune disorders. Patients from the region as well as from all 50 states come to National Jewish Medical and Research Center for medical diagnosis and care. Patients receive superior care without regard to their ability to pay. Each year $7 to $10 million of free or heavily subsidized care is provided each year. Additionally, National Jewish has the only physician training program in the state that produces doctors who can be certified as experts in environmental and occupational medicine.

National Jewish was recently ranked as the best hospital in the nation for excellence in treating respiratory diseases in U.S. New and World Report's "America's Best Hospitals." American Health magazine termed National Jewish one of the finest U.S. hospitals in allergy, immunology and pulmonology for both adult and pediatric patients. The Institute for Science and medicine rated National Jewish among the top 10 independent biomedical research institutions—of any kind—in the world, and the only one that also provides patient care. It was ranked as one of the three most influential research institutions for immunology and as the number one private immunology research institution in the world.

Partnerships with other academic institutions.—National Jewish has close affiliations on many research, educational and clinical projects including affiliations with: The Department of Preventive Medicine at the University of Colorado Health Sciences Center, researchers at the University of Colorado Boulder and Denver campuses, the Department of Industrial Hygiene at Colorado State University, and a number of governmental and non-profit research organizations in the region.

Partnerships with governmental agencies.—In addition to conducting research directly funded by several agencies, National Jewish faculty provide advice and consultation to local, regional and Federal government offices, including: the Colorado Department of Health and the Environment, the Governor's Air Toxics Science Advisory Committee, the U.S. Department of Energy Beryllium Standard Advisory Committee, oversight Boards for Hanford Reservation in Washington State, the Nevada Test Site, and Los Alamos National Laboratories, the EPA air pollution research advisory panel, and the OSHA Metalworking Fluids Standards Advisory Committee, and both CDC/NIOSH and NIH research advisory committees.

Partnership with community health organizations.—Faculty members conduct community outreach, speaking at local hospitals on environmental health. Three of our faculty have served as presidents of the Rocky Mountain Academy for Environmental and Occupational Medicine, the regional society for all physicians practicing in this field.

Partnership with regional industry and labor.—National Jewish has helped organize and conduct medical education and medical surveillance programs for many regional industries, helping them to protect employees from hazards in the workplace.

National Jewish proposes to establish a public/private partnership with the Federal Government in support of the establishment of the "Center for Environmental Health Research and Service." This partnership will cover the cost of the construction of a new, 50,000 square foot, state of the art facility which will house all basic and clinical environmental research, clinical care, outpatient services, training and consulting services affiliated with the Environmental Health Research and Sciences program.

The Department of Health and Human Service's, Health Resources and Services Administration (HRSA), directs national health programs which improve the health of the Nation by assuring quality health care to underserved, vulnerable, and special-need populations and by promoting appropriate health professions workforce capacity and practice, particularly in primary care and public health.

The activities proposed at the Center for Environmental Health Research and Service are in keeping with HRSA's mission of detecting and alleviating unhealthful conditions of the environment as well as for providing appropriate primary, supplemental and clinical care for diseases caused or aggravated by the environment compliment and forward HRSA's multifaceted mission.

The total cost of the proposed facility is $14 million. National Jewish received a $1 million HRSA grant from this Subcommittee last year to carry out the initial phases for the construction of the CEHRS. National Jewish seeks $5 million in HRSA follow-on funding in fiscal year 2000 to help construct the new Center.

Thank you.

PREPARED STATEMENT OF THE NATIONAL PSORIASIS FOUNDATION

Mr. Chairman and Members of the Appropriations Subcommittee: Thank you for allowing the National Psoriasis Foundation (NPF) this opportunity to present written testimony to the committee on the subject of NIH appropriations, particularly as regards skin disease research conducted through the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

We write you as advocates for 7 million American men, women and children with psoriasis—a chronic, debilitating skin disease. Psoriasis is a common disease that affects one person in fifty, and yet it is a disease without a cure and without universally effective treatments. Until a cure or more effective treatments are found, millions of people with psoriasis face a lifetime fighting this disease.

We write to urge the committee to approve an increase of 15 percent over current funding levels for NIAMS for fiscal year 2000. This increase, which would further the commitment to double the NIH budget in five years, is critical to the ability of our nation's scientists to uncover the secrets of diseases such as psoriasis, which cost our nation so much.

—Over three billion dollars are spent annually on psoriasis treatment
—Each year psoriasis patients make approximately 2.4 million visits to dermatologists
—Each year several hundred people with debilitating psoriasis are granted disability by the Social Security Administration
—One person in five with psoriasis has disease that interferes with their ability to perform everyday tasks, including employment and childcare

Psoriasis is chronic, unpredictable and often unrelenting. Treatments may be successful for only relatively short periods of time for only some people. The thick, red, scaly patches on any or all parts of the body can limit daily activities and interfere with physical, occupational and psychological functions. Skin affected by psoriasis may itch, burn, sting, and easily bleed. Physically, psoriasis can range in severity from mild to disabling. Three-quarters of a million of the people diagnosed with psoriasis are under the age of 10.

As many as 20–30 percent of people with psoriasis, over one million people, also suffer from an associated arthritic condition, psoriatic arthritis. Psoriatic arthritis can also cause significant disability and impairment of quality of life.

The occupational impact of psoriasis and psoriatic arthritis not only poses a significant economic burden for this nation but also a significant hardship for the person with psoriasis:

"I started dealing with psoriasis fairly recently. My ears were afflicted for years—then my scalp started. And I went to the dermatologist. That was in January 1998. Since then, the psoriasis has increased and covers practically my whole scalp, both ears, and is now on my face.

" Although I realize I am one of the lucky ones, as I have had only fairly minor complications and have very little truly visible patches, it is an extreme bother. Missing out on playing with your kids, being ostracized as a child, would be the worst! And I'm very concerned that it could advance to that stage without effective treatment.

"I've spent lots of money—nothing compared to what my insurance company has spent—to fight psoriasis. In the course of a year, I have tried approximately 10 different shampoos—to no avail. I've also tried at least that many topical solutions—and none of them have worked. (Some relieved my symptoms temporarily.) To mention nothing of the rounds of injections I've received in my scalp—only to have the symptoms go away for merely a week or so.

"I've wasted seemingly endless amounts of time attempting to combat the disease. Going to the doctor, going to the pharmacy, researching, and trying out the newest prescriptions. Not to mention the time it takes to care for your psoriasis and the frustration it causes. And the concern that it will appear in other places, become even more of a problem (get infected, etc.)

"I'm young and a professional. Having 'dandruff,' constantly scratching, having blotches all over your face, or having 'greasy' hair from the topical medicine of the day is completely unacceptable in the workplace. It makes people think that you don't take care of yourself and aren't 'put together'—presenting a poor professional picture and perhaps ultimately working against your career. The symptoms can be truly embarrassing. And my sister tells me that it's taboo to talk about it with others.

"As with any disease that doesn't have a cure at present, research is the only way."

CATHERINE SCHELIN, *Washington, DC.*

Moderate-to-severe psoriasis, which affects as many as 2 million American men, women and children, dramatically inhibits a person's ability to maintain a normal, healthy, active lifestyle. Plaques on large areas of their skin may restrict their movement and the pain and itching often disrupts their sleep and their ability to work. Psoriasis on the palms of the hands or the soles of the feet can be disabling, preventing people from grasping a pen, holding their child, walking or standing.

These people have psoriasis that cannot be controlled by simple topical treatments. To manage their disease they require expensive, inconvenient phototherapy radiation treatments in a doctor's office, or oral systemic medications that put the patient at risk of serious side effects. Some types of psoriasis require hospitalization and can even be life threatening.

Emotionally, psoriasis can be devastating. The social rejection and physical suffering of psoriasis has led people to suicide. Many psoriasis sufferers struggle throughout their lives with pain, embarrassment, and shattered self-image.

"This disease can be incredibly frustrating, discomforting, and embarrassing. Every person with psoriasis has their own way of coping with this chronic disease, whether its feelings of depression, denial, shame, or a sense of loneliness. My life has changed in many ways. And as a result, I have become very active in my business career and try not to focus on how psoriasis affects every day of my life. Whether it has limited my ability to wear shorts in the summer, inhibited me from playing sports, or prevented me from pursuing a personal relationship for almost 4 years, it has scarred me emotionally. I have gone from being a very confident, outgoing young man to somewhat of a loner when it comes to pursuing a personal relationship."

STEVE WISEMAN, *Maryland.*

Like diabetes, arthritis, and heart disease, psoriasis requires lifelong treatment. Indeed, a recent survey shows that 48 percent of Americans would actually prefer to have heart disease, asthma or diabetes, all of which are life-threatening, instead of psoriasis.

"Sometimes, I wonder whether suffering from an internal condition, such as diabetes or heart disease, would make life easier. Instead of people staring and making horrible remarks, people would be sympathetic. We live in a shallow world and people with external problems (psoriasis, eczema, and other physical handicaps) have to face the brutal nature of our world on a daily basis."

STEVE WISEMAN, *Maryland.*

Unlike diabetes or heart disease, however, psoriasis is not a top priority for many researchers or pharmaceutical companies. But thanks to focus and funding provided by NIAMS, recent research has identified several possible sites for the genes that may cause this inherited condition. Scientists tell us that a real cure for psoriasis will come from these critical genetics studies.

Other research has begun to pinpoint the autoimmune component of the disease, providing valuable targets for drug development. Many of the same autoimmune processes that researchers have discovered at work in diseases such as rheumatoid arthritis and Crohn's disease are also active in psoriasis. For instance, researchers are now finding that testing new therapies in psoriasis can be an effective way to determine if a new drug is safe and if it may work in these other diseases. This research must be aggressively continued, as research in one disease may very well benefit others.

Effective treatments and a cure for psoriasis are within reach, and sufficient funding will enable medical science to complete the puzzle and find a cure for this chronic, costly, and devastating disease. This will not only benefit the seven million American children and adults now suffering with this chronic disease, but will also help the 200,000 people who are diagnosed each year with new cases of psoriasis.

Better treatments or a cure for psoriasis will result in savings both to the public and the government in treatment costs, lost workdays, and Social Security disability claims. Beyond these valuable dollar measurements, an increase in federal spending for such biomedical research will directly result in an immeasurable improvement in the quality of life for these millions of affected Americans.

Therefore, on behalf of the members of the National Psoriasis Foundation, and the 7 million Americans with psoriasis, we again strongly urge you to approve an increase of 15 percent over current funding levels for NIAMS for fiscal year 2000. This increase will have significant health and socioeconomic benefits for the millions of Americans who are affected by psoriasis and by other diseases under the purview of NIAMS.

Thank you for your time and your support.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

Mr. Chairman and members of the Committee, the American Society of Tropical Medicine and Hygiene (ASTMH) is pleased to have the opportunity to present its views on fiscal year 2000 funding priorities to the Committee.

The ASTMH, founded in 1903, is a professional society of approximately 3,500 researchers and practitioners who are dedicated to addressing the growing global threat of tropical infectious diseases. The collective expertise of our members is in the areas of basic molecular science, medicine, vector control, epidemiology, and public health. ASTMH is the principal voice for tropical medicine research within this country.

A strong U.S. research agenda relating to infectious diseases is critical at this time when the ease of travel and openness of trade exposes the world's population, including U.S. citizens, to new and re-emerging infectious disease agents. In 1993, more than 27 million Americans traveled to the developing world risking infection from the many emerging and re-emerging infectious and tropical diseases. In 1998, an outbreak of severe chicken influenza in Hong Kong publicly raised the specter of another influenza pandemic such as that experienced in 1918, killing over 20 million globally. Two years ago it was Cyclospora, a parasite which entered the country via raspberries and lettuce imported from Central America. And we are all now familiar with the re-emergence of tuberculosis and emergence of new diseases such as Hantavirus respiratory syndrome within the U.S.

More than 30 new human pathogens have been recognized in the last 25 years. It also is evident in our new world economy that, in addition to humanitarian reasons, investments that help ensure healthy populations in developing countries contribute to the economic stability of these nations, which benefits the world's population as a whole. We must continue to be vigilant in our efforts to control and eradicate infectious diseases through prevention, treatment, and continued surveillance. As we approach the 21st century, it is time to protect our national security against biological and chemical attacks and declare war on infectious disease and antimicrobial resistance.

NATIONAL INSTITUTES OF HEALTH (NIH)

Mr. Chairman, the ASTMH thanks you and members of the Committee for your strong leadership in support of biomedical research funding. As a result of the 15 percent increase provided to the NIH in fiscal year 1999, new scientific and research opportunities are being pursued that hold the potential to enhance the quality of life for all Americans and improve health outcomes around the world. Your actions reflect the extraordinary importance of biomedical research to our national interest and are also helping to attract growing numbers of young scientists to the fields of academia and basic and clinical research.

ASTMH commends Congress for pursuing budget increases that will effectively double the NIH budget by fiscal year 2003. Accordingly, we strongly support a 15 percent increase for NIH in fiscal year 2000 as advocated by the Ad Hoc Group for Biomedical Research. An appropriation of $18 billion for NIH in fiscal year 2000 will allow promising research avenues to be pursued, including the development of new vaccines and treatments for diseases such as malaria, dengue fever, cholera, diarrheal diseases, HIV/AIDS, and a myriad of other viral bacterial, fungal and parasitic disease agents.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The NIH's tropical disease research program is funded primarily by the National Institute of Allergy and Infectious Diseases (NIAID) and there are several important on-going issues relating to NIAID's research efforts that we would like to highlight.

Malaria.—Globally, infectious diseases are the leading cause of morbidity and mortality, accounting for 1–3 times the mortality and morbidity resulting from heart disease, cancer and stroke combined. Of these infectious diseases, malaria continues to be the most devastating with a World Health Organization estimate of nearly 500 million clinical cases and up to 2.7 million deaths annually. Every 30 seconds a child somewhere dies of malaria. Even in the U.S., over 1,000 cases of malaria are reported every year, with local transmission being documented by the Center for Disease Control and Prevention (CDC) in California, Florida, New Jersey, New York, Texas, Michigan and Georgia.

The Society applauds NIH Director Dr. Harold Varmus and NIAID Director Dr. Anthony Fauci for their continued leadership at home and abroad in advancing the international collaborative research project, the Multilateral Initiative on Malaria,

and for implementing NIAID's Research Plan for Malaria Vaccine Development. Malaria is a complex disease and its control will require a significant research effort in vaccine development as well as other research areas. We are pleased that NIH recognizes this and is willing to commit significant resources towards solving this problem. We urge the Committee to be supportive as well.

INTERNATIONAL TROPICAL DISEASE RESEARCH PROGRAMS

NIAID's support for international tropical disease research is critical for advancement of our scientific understanding of emerging, re-emerging and other tropical diseases. Through these programs, U.S. researchers are able to collaborate with their colleagues worldwide in efforts that are absolutely mandatory to gain research expertise in areas endemic for tropical infectious diseases. The International Collaborations in Infectious Disease Research and the Tropical Disease Research Units are two programs in particular have been critical in these efforts.

For example, the International Collaborations in Infectious Disease Research program supported collaborative studies conducted by Johns Hopkins University that have led to the development, standardization and application of a diagnostic assay, under field and clinical conditions, for infection with Taenia solium, the pig tapeworm that is responsible for neurocysticercosis in humans. This test is the current standard for the serological detection of infection and is providing a more reliable assessment of the extent of the disease in Peru and other countries. These collaborative studies in Peru have demonstrated that oxfendazole is an inexpensive, effective and safe single-dose therapy for cysticercosis in pigs.

Tropical Disease Research Units have assisted research conducted by the University of California, San Francisco, that has led to the validation of cysteine proteases of trypanosomatid protozoa as targets for drug development. A number of chemical compounds have been synthesized and have been shown to inhibit the parasite enzymes and to cure animals experimentally infected with Trypanosoma cruzi and Leishmania spp., the causative agents of human Chagas Disease and leishmaniasis, respectively. Lead compounds are being evaluated for their toxicological and pharmacological properties. Preliminary evidence indicates that these lead compounds are selectively toxic for the parasites and exhibit clinically useful pharmacological properties.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) is a unique component of NIH whose mandate is to support training in biomedical research on behalf of the developing nations of the world. The ASTMH membership acknowledges the significant contributions of the FIC/NIH in overall support of tropical disease research of direct vital importance to American travelers, servicemen, missionaries, Peace Corps volunteers, and foreign service officers, among others. Less obvious are the indirect benefits of training in tropical disease research for our foreign biomedical counterparts. Healthier workforces are more productive and contribute to the economic health and stability of developing countries, and global peace. Support for disease control activities is not only right for humanitarian reasons, but it is also serves our national interest.

Many of the university and private corporate investigators and clinicians in ASTMH have benefited from the professional interactions with foreign scientists sponsored by FIC. Much of the FIC investment is recycled in U.S. universities and laboratories on behalf of outstanding foreign trainees and their American sponsors. The modest investment in the FIC has had a major impact on global disease control and has led to important scientific discoveries resulting in improved health outcomes here at home and around the world. We urge the Congress to provide a 15 percent increase for the FIC in fiscal year 2000.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The ASTMH also strongly supports CDC activities to combat infectious diseases. We thank the Committee for the $24.7 million increase provided to CDC's infectious diseases program in fiscal year 1999. We are especially pleased with the increases provided for the National Center for Infectious Diseases emerging and re-emerging infectious diseases program.

The ASTMH supports the Administration's fiscal year 2000 budget request of $181,926,000 for CDC infectious diseases programs, an increase of $44 million over the current year budget. This level of funding will enable the CDC to implement its strategic plan to protect the public from new and re-emerging infectious disease and new threats to our nation's domestic health over the next five years, "Preventing Emerging Infectious Diseases: A Strategy for the 21st Century." As we enter

the new millennium, the CDC must enhance efforts, working with other U.S. agencies and international organizations, to combat infectious disease, continue to ensure the safety of the nation's food supply, address the growing problem of antimicrobial resistance, and build our nation's capacity to respond to threats of bioterrorism.

Recent Senate hearings on bioterrorism have exposed how ill-prepared we are at the present time to protect the public in the event of a biological or chemical warfare attack and highlighted the urgent need to strengthen the country's public health infrastructure's capacity to respond under such circumstances . The proposed fiscal year 2000 budget request for the CDC focuses on the need to develop emergency preparedness at all levels of government, including establishing a training/technology transfer program for state-of-the-art rapid diagnosis to state and local health departments to support and strengthen our public health laboratories, and improve surveillance and reporting systems.

The fiscal year 2000 budget request will also enhance the National Food Safety Initiative as part of an ongoing effort to build a national early warning system for hazards in the food supply. Funds allocated to the CDC will be used to enhance surveillance and outbreak investigation capabilities at all levels of government, conduct detailed analyses of the economic impact of food borne outbreaks, and design training and education tools to assist health professionals in the diagnosis of food borne pathogens by laboratorians and provide school health education regarding food safety.

CONCLUSION

As the 20th Century comes to a close we must change our vision of U.S. national security. We are at war, but this time infectious diseases are our enemy. Infectious disease agents have no respect for political borders, and social or economic status do little to ensure safety from new diseases or those re-emerging as a consequence of drug resistance or other causes. To be prepared for a battle that undoubtedly will intensify, we must have adequate surveillance systems and modern infrastructure, coupled with scientific expertise in both basic and clinical research, if we are to develop the tools necessary to rapidly respond to, and control, the threats posed by infectious diseases.

The ASTMH greatly appreciates your support of these activities. We urge you to continue your efforts to double the NIH budget over the next five years and towards this end we request a 15 percent increase for the NIH budget in fiscal year 2000. We also request that the Committee support the Administration's proposed increase of $44 million for the CDC's emerging infectious diseases activities.

PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION OF AMERICA

On behalf of the Spina Bifida Association, please accept this testimony to the Committee record. SBAA applauds the subcommittee for the 14.7 percent increase in NIH funding for fiscal year 1999 and thanks the Subcommittee for a 12.5 percent fiscal year 1999 increase for the CDC. Through the appropriation of funds for spina bifida research, you will provide a vehicle to greatly improve the health and welfare of persons with spina bifida, the number one most frequently occurring permanently disabling birth defect in our country today.

The Spina Bifida Association of America was founded in 1973 and serves as the national representative of over 70 affiliates, chapters, and group members nationwide and represents children and adults with spina bifida, their family members, health care professionals, allied health professionals, educators, and interested members of the general public. The mission of the Spina Bifida Association of America is to promote the prevention of spina bifida and to enhance the lives of all affected.

Spina bifida is the most frequently occurring permanently disabling birth defect. It affects approximately one out of every 1,000 newborns in the United States. More children have spina bifida than muscular dystrophy and cystic fibrosis combined. Spina bifida results from the failure of the spine to close during the first month of pregnancy. In most cases, the spinal cord protrudes through the back covered only by skin or a thin membrane. Surgery to close the back is performed within 24 hours after birth to minimize the risk of infection and to preserve remaining function in the spinal cord.

Spina bifida is one of the most devastating of all birth defects. It affects an individual neurologically, orthopedically, and urologically. It is typified by hydrocephalus, paralysis and mobility impairment, and bowel and bladder incontinence. Conditions associated with spina bifida include seizure disorders, malformation of

the brain stem, scoliosis, tethered spinal cord, respiratory disorders, sleep apnea, central auditory processing disorders, gastrointestinal disorders, sexual dysfunction, attention deficit disorder, immunological disorders, decubitus ulcers, urinary tract infections, severe depression, arthritis, limb deformities, and chronic pain. The average lifetime medical cost for a person with spina bifida is $535,000. However, the cost in many cases exceeds $1.2M. It is not uncommon for a child with spina bifida to undergo four to six major surgeries before they reach the age of three, and ten to twelve surgeries before their tenth birthday.

Incredibly, the incidence of spina bifida can be reduced by 50–75 percent, if all women of childbearing age would consume 0.4 mg of folic acid, a B vitamin, daily prior to becoming pregnant. The U.S. Public Health Service made the daily consumption of folic acid to decrease the incidence of spina bifida a formal health recommendation in September, 1992. Unfortunately, less than 13 percent of women are aware of the health recommendation, and the frequency of occurrence of folic acid preventable spina bifida remains unchanged.

Although there has been research in the area of preventing spina bifida and some understanding secondary conditions, there has been very, very little research done in the areas of treatment protocols for persons with spina bifida and in identifying effective intervention strategies to prevent spina bifida's many associated conditions. This year NIH expects to sponsor research grants totaling approximately $8.9M on spina bifida research within the National Institute on Neurological Disorders and Stroke (NINDS) and the National Institute of Child Health and Human Development (NICHD).

Today we are witnessing America's first generation of adults living with spina bifida. 95 percent of children born with spina bifida have a condition known as hydrocephalus, a swelling of the brain caused by a build-up of cerebrospinal fluid. Prior to the late 1960's and early 1970's most children born with spina bifida died, but the widespread use of the shunt in the late 60's changed this. The shunt is a small tube that is inserted immediately after birth which drains excess fluid from the brain to the abdomen eliminating hydrocephalus. Now, 85–90 percent of babies born with spina bifida survive into adulthood, 70–80 percent have normal IQs, and the first generation of persons with spina bifida are surviving into and beyond young adulthood. And, with no change in the frequency of occurrence of spina bifida prior to 1992, and very little decrease since 1992, their numbers are growing, and will continue to grow. Persons with spina bifida total in excess of 70,000 and the number is increasing by several thousand each year.

We request that the Subcommittee to consider two areas of funding. The first is to support a NIH Consensus Conference to identify and to evaluate the existing scientific data regarding spina bifida and to develop a plan that prioritizes research that identifies early intervention strategies and treatment protocols that prevent or lessen the most pressing conditions affecting persons with spina bifida. The second is to appropriate additional funding to the CDC to allow them to vigorously promote the U.S. Public Health Service folic acid spina bifida prevention recommendation to reduce the incidence of occurrence of spina bifida.

NIH CONSENSUS CONFERENCE

As the first generation of persons with spina bifida grows into adulthood, their care is an emerging health discipline. But, the road map is unclear and fragmented, signposts few, and facts elusive. A review of the published medical literature provides minimal information about aging issues and secondary conditions among persons with spina bifida. Moreover, there is very little information regarding the impact of commonly practiced interventions over a lifetime. There is sparse scientific evidence indicating which protocols are successful. Research areas and secondary conditions that have been recognized as issues began as anecdotal stories. With the exception of $8.9M in fiscal year 1999, very little is being done to discover strategies and promote health and wellness for persons with spina bifida.

Persons with spina bifida experience lifelong debilitating medical conditions. Individuals with spina bifida experience recurring and debilitating urinary tract infections. Treatment often requires 3 to 5 days of hospitalization with IV antibiotics. Each episode, of which there are many, for each person with spina bifida, is painful, costly, and life disruptive. We need effective protocols to predict and manage this recurring condition.

Disturbingly, there is growing evidence, that many persons with spina bifida in their late teens and twenties suddenly die from brain stem collapse. Also, anecdotal stories are widespread that cancer occurs at higher rates in persons with spina bifida. We need to find if and why this is true.

Learning disabilities and attention deficit disorder are also problems that seem to occur in persons with spina bifida. Very little research has been conducted on the person with spina bifida and learning disabilities or, more specifically, in identifying the role of the shunt as a precursor to learning disabilities.

As many as 73 percent of persons with spina bifida are allergic to latex as measured by history or blood tests. Reactions can be as severe as life threatening changes in blood pressure and respiration. Yet we are surrounded by latex from clothing to toys to medical equipment. What precautions can the person with spina bifida take? How can we best educate the health care field to this hidden danger for persons with spina bifida?

The questions are many, the answers are few, the histories spotty, the treatment trial and error. An NIH Consensus Conference is the much needed first step in the process to evaluate the minimal scientific data, sort out the science, prioritize issues and research, and develop a plan for action.

INCREASE CDC BUDGET FOR FOLIC ACID AWARENESS

We have the means to prevent the occurrence of spina bifida by up to 75 percent if we could only educate women to consume folic acid. That's a reduction of up to 75 percent of persons experiencing the devastating medical conditions I have described. It is also a reduction of up to 75 percent of the staggering medical cost of $535,000 associated with each case of the birth defect.

We must educate the 60 million American women of childbearing age to consume 0.4 mg of folic acid daily prior to becoming pregnant. In the United States almost 4,000 pregnancies per year or 12 pregnancies per day are affected by spina bifida and anencephaly. Any woman can have a child with spina bifida. Ninety-five percent of all affected pregnancies occur among women with no history of birth defects in their families. Women who have previously had a spina bifida affected pregnancy are 20 times more likely to have additional affected pregnancies. Hispanic women and Caucasian women of Celtic descent have a higher risk. In short all 60 million American women of childbearing age are at risk of having a child born with spina bifida.

Although we do not fully understand the developmental failure that causes spina bifida, we do know that 50–75 percent of spina bifida births are preventable when women of childbearing age take 0.4 mg every day before they become pregnant. The reason the folic acid needs to be consumed prior to becoming pregnant is that the neural tube develops in the first 18–30 days of pregnancy, often before a woman realizes she is pregnant.

An essential vitamin, folic acid plays an important role in cell division and growth. In addition to ensuring the healthy development of the fetus, it is beneficial throughout life in the maintenance of cells particularly along the internal and external linings of organs. Some studies have linked folic acid to a reduction in heart disease, cervical and colon cancers, and the reduction in risk of other birth defects such as cleft lip, cleft palate, and heart defects. SBAA supports further research in this area, but more importantly recognizes the immediate need to substantially increase the CDC budget for public awareness and education campaigns and widespread dissemination of the 1992 U.S. Public Health service recommendation.

The pressing need for greater education and awareness is supported by a 1998 March of Dimes survey conducted by the Gallup Organization under a grant from the Centers for Disease Control and Prevention. The survey revealed the following about women and folic acid:

—Most women, who take multivitamins containing the B vitamin folic acid, take them too late to prevent spina bifida.

—Only 29 percent of American women 18–45 years of age who are not currently pregnant take a daily multivitamin containing folic acid. For those 18–24 years, the percentage drops to 19 percent, yet this age group accounts for 32 percent of all births in the U.S.

—The number of women who have heard of folic acid has increased from 52 percent in 1995 to 68 percent today. Yet there has been no corresponding increase in the number of women taking a multivitamin containing folic acid every day.

—Only 13 percent of those surveyed knew folic acid prevents birth defects, and only 7 percent knew that folic acid needs to be taken daily before pregnancy.

Sadly, the epidemic of epidemic of folic acid preventable spina bifida continues unabated.

The Spina Bifida Association of America is requesting the subcommittee to increase the existing $1.5 million CDC folic acid awareness budget to $20 million, the amount recommended by the National Task Force on Folic Acid. Compared to the average medical cost, and medical cost only, of $535,000 for each person with spina

bifida, the current budget figure pales embarrassingly. SBAA understands budgetary constraints, but our requested increase for CDC is modest when compared to the cost per incidence and the numbing prospect of living a life affected by this devastating birth defect.

Spina bifida, many Americans find it difficult to pronounce; many, many more Americans do not realize that the population of persons with spina bifida is growing and aging; they are not aware of the depth of spina bifida's life long medical odyssey. Eighty-seven percent of the 60 million women of childbearing age in the United States do not know that up to 75 percent of spina bifida births can be prevented. And, these are situations we can not ignore. An NIH Consensus Conference will begin the process of improving the quality of life for the tens of thousands of persons with spina bifida. Greater support of folic acid education and awareness efforts through an increase in CDC funding will benefit countless numbers of yet to be born Americans.

PREPARED STATEMENT OF MICHAEL Q. FORD, EXECUTIVE DIRECTOR, NATIONAL NUTRITIONAL FOODS ASSOCIATION

My name is Michael Ford. I am Executive Director of the National Nutritional Foods Association (NNFA), a trade association representing 3,000 independent health food stores and 1,000 manufacturers, distributors and suppliers of natural health products, including organic and natural foods, natural ingredient cosmetics and dietary supplements.

CONGRESSIONAL MANDATE MIRRORS CITIZEN DEMAND

National interest in access to and reliable information on safe, effective vitamins, minerals, herbs, amino acids and other dietary supplements has grown steadily since the Dietary Supplement Health and Education Act (DSHEA) unanimously passed the House and Senate to become the law of the land in 1994.

Approximately 100,000,000 Americans are taking dietary supplements, spending, by some estimates, as much as $11.5 billion a year in health food stores alone. Americans are looking to safe, natural alternatives to prescription drugs to treat and prevent disease, and to maintain good health by supplementing inadequate diets with vitamins and minerals.

NUTRIENTS CAN PREVENT CHRONIC DISEASE

We are entering a new era of recognition of the value of natural pathways to good health. For example, the Food and Nutrition Board of the National Academy of Sciences, which devises Recommended Daily Allowances for nutrients for the Food and Drug Administration, has issued the first of a series of reports presenting revised nutrient intake guidelines. Originally introduced in 1941, RDAs were intended to prevent classical nutrient deficiency diseases nearly extinct in the US today, such as scurvy, beriberi and rickets. Now, these reports are revising and expanding RDAs to reflect compelling evidence which supports the use of nutrients to help prevent chronic disease, such as osteoporosis. We agree with the Chairman of the Food and Nutrition Board, who last year characterized this approach as ". . . a major leap forward in nutrition science."

Similarly, the report of the President's Commission on Dietary Supplement Labels endorsed continued research on the benefits of dietary supplements in health promotion and disease prevention. The Commission hailed the increasing research-based documentation of the benefits of dietary supplements in maintaining health and preventing chronic disease and other health-related conditions, and called for continuation of this welcome trend. NNFA continues to endorse the Commission's recommendation that, " the public interest would be served by more research that assesses the relationships between dietary supplements and maintenance of health and/or prevention of disease."

HERBS AND BOTANICALS ARE BENEFICIAL, COST-EFFECTIVE

In addition to support for these kinds of exciting new findings on the health benefits of nutrients, NNFA urges the Committee to support research on medicinal herbs and botanicals, also classified as dietary supplements under the DSHEA. The results of a study on ginkgo biloba, published recently in the October 22, 1997 Journal of the American Medical Association, indicates that administration of this herbal extract, recognized for centuries in Chinese medicine for its ability to stimulate and improve blood circulation in the brain, could delay the onset of Alzheimer's Disease for up to six months. This could represent tremendous savings of lives and dollars

from a disease which costs society $90 billion a year. Other studies show saw palmetto more effective than prescription medicine at reducing benign prostate enlargement, with far less expense and no reportable side effects. And, on the day before I testified before this Committee last year, Harvard University announced the results of a 14-year study of 80,000 nurses, concluding that large amounts of vitamin B6 and folic acid could prevent heart attacks by an astounding 51 percent.

Millions of Americans are turning daily to herbal remedies and seeking primary health care from the alternative, holistic providers who prescribe them. There is an urgent need for a dramatic increase in support for research on herbs and botanicals, justified by consumer demand and the Congressional intent expressed in DSHEA. The Dietary Supplement Commission report recommends that, ". . . Federal agencies continue to support research on the health benefits and safety of dietary supplements. Research should be expanded beyond the traditionally supported areas associated with vitamin and mineral supplements and include research on some of the more promising botanical products used as dietary supplements." NNFA wholeheartedly agrees.

Ours is one of the few cultures in the world for whom the prevention and treatment of disease with non-prescription herbal medicines is the exception rather than the rule. This is largely due to the fact that foreign research oftentimes is deemed unacceptable by the Food and Drug Administration for use in justifying health claims for herbs and botanicals. We urge the Committee to provide the adequate funding for research on the safety and benefits of medicinal herbs.

FULL FUNDING FOR THE NIH OFFICE OF DIETARY SUPPLEMENTS

The Office of Dietary Supplements (ODS) was established at the National Institutes of Health by DSHEA, to stimulate, coordinate and disseminate the results of research on the benefits and safety of dietary supplements in the treatment and prevention of chronic disease. Though authorized at $5 million per year by DSHEA to carry out its lofty mission, ODS has been woefully underfunded and allotted fewer than 2 full-time employees (FTEs). Despite these severe financial constraints, ODS has done an admirable job in attempting to meet its mandate. While this is commendable, the Congressional mandate for ODS is yet unmet.

NNFA agrees with the President's Commission on Dietary Supplement Labels that the ODS must be fully-funded at $5 million. Says the Commission report, if fully-funded, ". . . ODS could play a valuable role in providing consumers with information about dietary supplements . . . including [the] promotion of scientific studies on potential roles of dietary supplements in health promotion and disease prevention. Appropriations as authorized by DSHEA are essential if ODS is to meet [the] mandates of the Act." ODS deserves this Committee's support and that of the NIH itself. In particular, we urge continued funding for the botanical research initiative which began this year at the ODS.

OFFICE OF COMPLIMENTARY AND ALTERNATIVE MEDICINE

In 1992, Congress directed the National Institutes of Health to establish the Office of Alternative Medicine with the expressed task of assuring objective, rigorous review of alternative therapies to provide consumers reliable information. Funding for the Office has grown since its creation, and last year this Committee recognized that the fiscal year 1998 funding of $20 million provided for this office was an absurdly infinitesimal percentage of the overall NIH budget. Thanks to the profound interest of this Committee, in fiscal year 1999, the Office of Alternative Medicine became the Center for Complementary and Althernative Medicine, with a $50 million budget and authority to set its own agenda. This has given alternative research a well-deserved boost and is more in line with the health choices of most Americans.

Indeed, findings from the "National Survey of Alternative Medicine Use," published in the January, 1993 New England Journal of Medicine, reveal that Americans made an estimated 425 million visits to alternative medical therapy providers in 1990, exceeding the 338 million visits made to all US primary care providers that year. The survey also showed that out-of-pocket expenditures associated with alternative therapies totaled $10.3 billion in 1990, approaching the $12.8 billion in out-of-pocket expenses incurred for all U.S. hospitalizations during the same period.

NNFA asks the Committee to continue this most welcome trend. We ask that the NIH National Center for Complementary and Alternative Medicine receive an increase in funding for fiscal year 2000 that is at least equal in percentage to the overall increase Congress provides for NIH.

DEMONSTRATION PROJECTS AT AHCPR AND HFCA

The Agency for Health Care Policy and Research (AHCPR) is often directed by the Committee to pursue projects designed to research the cost-effectiveness attendant to novel approaches to the treatment and/or prevention of illness. The time is right for investigation of the worthiness of certain dietary supplements, based on well-designed, cost-effectiveness research.

Every year, treatment of chronic conditions and illnesses—from flus and colds to hypertension to dementia and Alzheimer's disease—generates enormous publicly and privately funded health care expenditures. There exists an opportunity to trim such burgeoning costs through prevention and/or treatment of these chronic ailments—or delay of their onset—with safe, effective, low cost dietary supplements. NNFA is confident that basic research at NIH can lead to appropriately structured, cost/outcome research at AHCPR which would demonstrate the value of dietary supplements in comparison to contemporary medical intervention. This evidence can, in turn, lead to HCFA projects to determine if a policy of reimbursement could be established.

Despite the growing popularity and demand for herbs and nutritional supplements, and their widespread use for prevention and intervention of chronic illness, precious few large-scale outcome studies on American populations are available to give health professionals the information they need to make decisions on alternatives to contemporary medical approaches. Echinacea and goldenseal have been shown to be effective in preventing and treating colds and flus; ginkgo has been show to forestall dementia and the onset of Alzheimer's disease; herbal/nutritional combinations have been shown to provide control for hypertension without the side effects which cause many patients to stop using their prescription medicine; similarly, saw palmetto effectively shrinks benign prostate enlargement without side effects affecting normal body function.

NNFA believes that a sufficient body of botanical and nutrient research may exist in certain instances, to whet AHCPR's appetite and to warrant Congressional consideration of cost-effectiveness studies in this area.

NNFA urges the Committee to consider directing AHCPR to work with the Office of Dietary Supplements and the Office of Complimentary and Alternative Medicine to review the existing outcome research on dietary supplements. The AHCPR could then investigate the feasibility, under appropriate protocols, of developing cost-effectiveness projects designed to compare the value of herbs and other dietary supplements in the treatment and prevention of chronic illness to typical medical approaches. The areas I have mentioned are but a few of the many possibilities which urgently present themselves for research and evaluation. Once the necessary biomedical and cost-effectiveness research have been completed, NNFA urges the Committee to direct HCFA to investigate the potential reimbursement for promising alternative therapies and treatments involving nutritional supplements and herbs.

A SOUND INVESTMENT IN THE HEALTH AND WELL-BEING OF ALL AMERICANS

Science and experience ably demonstrate a wealth of benefits attendant to the regular use of vitamins, minerals, amino acids, enzymes, herbs and botanicals—all classified by DSHEA as dietary supplements. Dietary supplements are allowing millions of American consumers to take charge of their own good health by safely and effectively preventing and treating a host of illnesses and conditions. The body of research supporting use of these products is impressive, but sorely requires immediate and dramatic expansion. NNFA urges the Committee to undergird the Congressional mandate expressed in DSHEA by investing in the scientific research which holds the key to our knowledge of the remarkable importance and value of dietary supplements.

Thank you.

PREPARED STATEMENT OF THE NATIONAL DEPRESSIVE AND MANIC-DEPRESSIVE ASSOCIATION

The National Depressive and Manic-Depressive Association (National DMDA) is pleased to have this opportunity to submit written testimony in support of fiscal year 2000 funding for mental health research supported by the National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH).

With more than 275 support groups in nearly every state, National DMDA is the nation's largest patient-run, illness specific organization committed to advocating for research toward the elimination of depressive illnesses, educating patients, professionals and the public about the nature and management of depression and manic-

depression as treatable medical diseases, fostering self-help, eliminating discrimination and stigma, and improving access to care. National DMDA was founded in 1986 and is headquartered in Chicago, Illinois. A distinguished scientific advisory board of more than 65 members reviews all materials published by National DMDA, and provides critical and timely advice on important research opportunities and treatment breakthroughs. This Board includes the leading researchers and clinicians in the field of depressive disorders.

THE IMPACT OF DEPRESSIVE ILLNESS

More than 18.4 million Americans suffer from unipolar depression every year. An additional 2.3 million people suffer from manic-depression or bipolar disorder. Women are more than twice as likely as men to experience major depression. Depression is the leading cause of suicide in America. Two out of three people with mood disorders do not get proper treatment because their symptoms are not recognized, are misdiagnosed, or due to the stigma associated with mental illness, are blamed on personal weakness.

According to a recent study by the World Health Organization (WHO), the World Bank, and the Harvard School of Public Health, unipolar major depression is the first-ranked leading cause of disability in the world today and bipolar disorder is the seventh-ranked cause of disability. The economic cost of depressive illnesses in the United States is estimated to be almost $44 billion per year in direct and indirect costs including absenteeism, mortality, and lost productivity. We cannot continue to ignore the seriousness of mental illness but must instead focus our research resources on better understanding depressive illnesses, improving treatments, and seeking a cure.

PROGRESS IN DIAGNOSIS, PREVENTION, AND TREATMENT

Research supported by the NIMH has led to many discoveries resulting in improved diagnostics, prevention, and treatments which has saved lives and billions of tax dollars. For example, more than $145 billion has been saved since 1970 as a result of the development of lithium treatment for manic-depression—almost $6 billion per year. A study supported by the NIMH showed that intervention to prevent depression in the workplace resulted in $1,314 per person in increased Federal and state taxes generated over a two and a half year period, with a cost of only $286 per person. Finally, it has been shown that every $1 spent on treatment of depressive disorders yields between $3 and $9 in net economic return on employment earnings.

NIMH-supported research has led to new and more effective medications for both depression and manic-depression. We also have a better understanding of depressive illnesses and are learning more about their impact on cardiovascular disease and stroke. The comorbidity of depression and alcohol and tobacco use is also becoming more clear. Research indicates that treating addiction and not depression leads to failure and relapse and vice versa.

Depressive and manic-depressive disorders are treatable medical illnesses, if diagnosis and treatment is received. However, one of the biggest obstacles to expanding access to services is the historical stigma surrounding mental health treatment, exemplified by arbitrary and unfair limits on access to mental health services by private health insurance plans. Increased public awareness and understanding of depressive disorders would contribute significantly to improved diagnoses and treatment rates for this potentially fatal illness. Tragically, individuals untreated or undertreated for major depression have a suicide rate in excess of 15 percent. For those with bipolar disorder, the suicide rate is in excess of 20 percent.

Genetics

Current research indicates that there is a genetic predisposition to manic-depression. Understanding the genetic basis of depressive disorders will lead to vastly superior methods of diagnosis, treatment and prevention. We support a continued strong investment in the NIH to achieve the completion of the human genome sequencing project, which will be critical to uncovering the genetic factors involved in mental illness and clarify the phenotypes of major mental disorders. We are pleased that NIMH is soliciting applications to collect a database of families with mental illness for genetic analysis as the science and technology becomes available in the near future. A high priority should also be the epidemiology and clinical evaluation of individuals with manic-depression and their family members.

Clinical research

National DMDA believes that the translation of research from the laboratory to the bench in a rapid and efficient manner is of paramount importance. This requires

a re-newed commitment to clinical research that is strongly supported at the highest levels of the National Institutes of Health (NIH). Furthermore, it requires that third party payers be required to support important patient care costs associated with the evaluation of promising therapeutics in order to facilitate the completion of clinical evaluation at the earliest possible moment. National DMDA is pleased with the progression of NIMH-sponsored clinical trials studying Hypericum perforatum (St. John's wort) and trials initiated within the last year to study treatments for children with schizophrenia, manic-depressive illness, depression, obsessive-compulsive disorder, and autism. We fully support NIMH plans to expand clinical trials of treatments for mental illnesses, with emphasis on clinical trials networks, developmental psychopharmacology, and an interventions infrastructure program.

Depression in children

Of particular concern to National DMDA is the issue of depressive disorders in children. Many children and adolescents suffer from depression, which in its most severe forms may lead to acts of violence including self-inflicted violence (suicide). The identification of depression in children as well as understanding the causes of depression and how best to intervene in childhood offers the best hope for preventing many cases of adult mental illness, including depression. National DMDA supports the aggressive research agenda NIMH is pursuing in this area, including a study to examine the course and outcome of bipolar disorder with onset in childhood and early adolescence, and research examining underlying bioregulatory processes, neurobehavioral systems, adolescent pubertal development and their links to major depressive disorder. We are particularly encouraged by NIMH efforts to strengthen the field of children's mental health research by creating new incentives for experienced investigators to move into studies of mental illness in children.

Bipolar disorder (manic depression)

The World Health Organization has identified that bipolar disorder is the seventh-ranked cause of disability in the world. Nearly 1 in 100 Americans suffers from manic depression yet research in this area has been seriously underfunded in recent years. In fact, in 1998, NIMH spent only $39 million on bipolar research and they are expected to spend just $46 million in fiscal year 1999. Thus, the government must continue to increase its investment in this important area of mental health research.

RESEARCH OPPORTUNITIES

National DMDA urges NIMH to pursue genetic research aggressively in collaboration with other NIH Institutes, academia, the private sector and by continuing studies of individuals with manic-depression and their family members. Other factors to examine in relation to genetics include building and refining knowledge of risk factors for depressive diseases, developing better predictors of risk, designing and piloting new screening measures, advancing early-intervention strategies for these risk factors, and studying the role stress and the environment play.

Neuroscience advances bring us to the brink of tremendous opportunities to understand underlying deficits in major mental disorders. We know more about neurobiology today than ever before and we must support, as a national priority, continued efforts to enable us to more fully exploit our recent advances. Flexibility of connections in the nervous system underlies many of the adaptive responses of the individual to the environment—including response to psychological and physical trauma and the more general processes underlying learning and memory—and such changes in the neural function are central to most mental disorders. The field is now poised for rapid strides into understanding these critical processes.

Other important opportunities include research to better characterize subtypes of depression; to find treatments with fewer side effects and understand the psychopharmacology of current antidepressants; and studies to close the gap between what is known about treating depressive illnesses and what is practiced particularly in managed care settings. These are just a few of the research areas where great opportunities exist.

The National DMDA looks forward to the release of the Surgeon General's Report on Mental Health later this year. It is our hope that it will generate greater awareness and understanding about the nature of depressive and manic depressive disorders as treatable medical illnesses and provide the catalyst for an aggressive mental health research agenda as we enter the 21st century.

FUNDING REQUEST

Of course, an aggressive research agenda requires sustained funding. While we recognize the Subcommittee's current budgetary constraints, National DMDA sup-

ports the effort initiated in fiscal year 1999 to double the budget for the NIH and NIMH by fiscal year 2003. This will allow us to take full advantage of the many exciting mental health research opportunities that exist today. To continue the glidepath towards achieving this important goal, we strongly support the fiscal year 2000 funding recommendation of the Ad Hoc Group for Medical Research Funding of $18 billion for the National Institutes of Health (NIH). The National DMDA supports a corresponding increase for NIMH.

Sustained, stable growth in funding for the NIH is needed to build upon past scientific achievements, address present medical needs, and anticipate future health challenges. Volatility and dramatic fluctuations in funding can be as harmful to the research enterprise as inadequate growth.

We appreciate your past support and look forward to working with you in the future to ensure a sustained commitment to mental health research. Together we can provide the gateway to new discoveries that will improve access to care and eliminate discrimination and the stigma associated with depressive and manic depressive disorders.

PREPARED STATEMENT OF THE SOCIETY OF TOXICOLOGY

The Society of Toxicology (SOT) is pleased to have this opportunity to present its views in support of fiscal year 2000 funding for the National Institutes of Health (NIH), and specifically for the National Institute of Environmental Health Sciences (NIEHS).

The Society of Toxicology (SOT) is a professional organization that brings together over 5,000 toxicologists in academia, industry, and government. A major goal of SOT is to promote the use of good science in regulatory decisions. With scientific data as our guide, we can use sound judgment in addressing numerous environmental issues. In particular, we work closely with the National Institute of Environmental Health Sciences (NIEHS) in addressing research related to environmental risk.

RESEARCH OPPORTUNITIES

Members of the Society of Toxicology strongly believe that our investment in biomedical research must be increased and sustained over the long-term if we are going to take advantage of the many exciting research opportunities which exist in the area of environmental health sciences. We are appreciative of the outstanding research efforts of NIEHS and are supportive of the research priorities identified by NIEHS Director Dr. Kenneth Olden.

Research supported by NIEHS is helping us to better understand how our environment affects our health. Research is being conducted to study the effects of air pollution such as ozone, particulate matter, and acid aerosols on our respiratory health. NIEHS supported research has shown the harmful health effects of lead especially in children, leading to the reduction of many sources of environmental lead. Researchers are now expanding their efforts to better understand why some people are more susceptible to environmental exposures than others. The Environmental Genome Project will further explore these questions and contribute to the development of improved prevention strategies and health. Finally, NIEHS under the auspices of the National Toxicology Program is making progress in developing new and innovative transgenic animal models to more efficiently test the toxicity of chemicals. This increased efficiency will allow for more chemicals to be tested more quickly.

SOT also supports the research NIEHS is conducting on the potential adverse effects of chemicals that are commonly referred to as endocrine disruptors. These are compounds in our environment which may have an affect on endocrine systems and on physiological processes which are dependent on normal functioning of the systems (e.g. reproduction and development). The Society is especially pleased that NIEHS is moving forward with a number of studies that will examine the linkage between exposure to alleged endocrine disregulating chemicals and diseases and disorders affecting women's reproductive health.

We also strongly support NIEHS involvement in the multi-agency effort to identify the research needs on the safety and efficacy of herbal medicines. According to the President's Commission on Dietary Supplements, some 1,500 to 1,800 botanicals are sold in the U.S. as dietary supplements or ethnic traditional medicines. As the use of these alternative therapies becomes more widespread, there is the need for scientifically valid information about both the benefits and risks of their use. The SOT is pleased that NIEHS is planning to conduct rodent studies of some herbal products for which there is no long-term data.

SUPERFUND BASIC RESEARCH PROGRAM

One program we would like to highlight is the Superfund Basic Research Program. This program is administered by NIEHS although it is funded through a pass through from the Environmental Protection Agency (EPA) to NIEHS. The Superfund Basic Research Program is the only scientific research program focused on health and cleanup issues for Superfund hazardous waste sites. It represents an important collaboration between EPA and NIEHS to ensure that environmental cleanup decisions are based on sound environmental health science.

The Superfund Hazardous Substances Basic Research Program supports university and medical school research to understand the public health consequences of local hazardous waste sites, as well as to develop better methods for remediation. Currently, there are 17 university-based research programs located in 69 institutions across the country. It is important to note that this is the only university-based research program that brings together biomedical and engineering scientists to provide the science and technology base needed for making accurate assessments of human health risks and developing cost-effective cleanup technologies.

The primary purpose of SBRP is to provide the scientific basis needed to make accurate assessments of the human health risks at hazardous waste sites. In addition, research data is used to determine which contaminated sites must be cleaned up first, to what extent clean up is needed, and how best to clean up contaminated sites in the most cost-effective manner. Research projects include basic research on the potential chemical effects on cancers, such as breast and prostate, birth defects, and other environmental health-related diseases.

Communities near hazardous waste sites want to know if hazardous chemicals are reaching their water or air supplies. They want to know if low levels of these contaminants affect their health and their children's health. They want it cleaned up. Our universities are responding with technology driven research efforts which are results-oriented and economically feasible, and are scientifically credible with the public. This is only possible because of the research effort funded through the Superfund Basic Research Program and administered by NIEHS.

FUNDING REQUEST

The Society of Toxicology strongly supports the effort initiated last year to double funding for the NIH by fiscal year 2003. To accomplish this, we urge the Committee to support the recommendation of the Ad Hoc Group for Biomedical Research Funding calling for a 15 percent increase for NIH in fiscal year 2000. The Society of Toxicology urges the Committee to provide a corresponding increase for NIEHS, given its important role in increasing our understanding of how the environment potentially affects our health. Whether it is exploring asthma incidence in children, testing the toxicity of chemicals, or better understanding the genetics underlying environmental risk factors, NIEHS supported research is leading the way in bridging the gap between public policy and environmental health science.

Thank you for considering our request. We look forward to working with you in the future as you determine the Committee's funding priorities.

PREPARED STATEMENT OF THE RESEARCH SOCIETY ON ALCOHOLISM

The Research Society on Alcoholism (RSA) is grateful for the opportunity to provide written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services. RSA is a professional research society whose 1,200 members conduct basic, clinical, and psychosocial research on alcoholism and alcohol abuse. We are indebted to this Subcommittee for its courageous support of medical research. The scientific community and the patients we serve are grateful that you have championed the cause of research on their illnesses.

One in ten Americans will suffer from alcoholism or alcohol abuse. The cost to the nation is nearly $167 billion annually, and the government bears close to half of these costs. Alcohol is a factor in 50 percent of all homicides, 40 percent of all motor vehicle fatalities, 30 percent of all suicides, and 30 percent of all accidental deaths. These statistics have a human face: family and friends killed by drunk drivers; frightened, abused children living with abusive alcoholic parents; good people who lose their jobs, their families, their health, and their dignity because they can't stop drinking.

Prohibition did not solve the problem of alcoholism, and current therapy is inadequate. Only research holds the promise of change, but alcohol research is woefully under-funded. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) funds over 90 percent of all alcohol research conducted in the United States. For

1999, the budget of the NIAAA is $259.7 million. We are committing to alcohol research only $1.56 for every 1,000 dollars lost from alcohol abuse and alcoholism and only $18 dollars for every affected individual. In 1997, NIAAA could fund just 27.8 percent of all grant applications; the comparable figure for NIH is 31.4 percent. Three times each year, members of the alcohol study section agonize over outstanding alcohol research proposals that will never be funded.

This inability to fund proposals comes at a time of unprecedented opportunities in alcohol research. Scientists funded by the NIAAA have identified discrete regions of the human genome that contribute to the inheritance of alcoholism. Genetic research will accelerate the rational design of drugs to treat alcoholism and improve our understanding of the interaction between heredity and environment in the development of alcoholism.

The development of effective therapies for alcoholism also requires an improved understanding of how alcohol affects the brain. This past year has produced exciting discoveries. Molecular biologists have demonstrated that alcohol targets specific regions of certain brain proteins to produce its effects. Learning the structure of alcohol's targets in the brain will allow scientists and the pharmaceutical industry to rapidly screen drugs that can block the effects of alcohol. Studies in fruit flies have demonstrated that a specific gene mutation can alter sensitivity to alcohol, an important predictor of the development of alcoholism in humans. Because genetic studies in fruit flies can be carried out rapidly, the development of this model will allow accelerate our understanding of how alcohol affects cell signaling in the brain.

Scientists have also been developing new ways of delivering psychotherapy to alcoholics, of engaging alcoholics in treatment, and of caring for the multiple problems of the alcoholics and their families. This ongoing process of developing and evaluating new therapeutic modalities has improved the treatment of alcoholic patients. Continued progress has been made in the development of treatments for alcoholism. Naltrexone, a drug that blocks the brain's natural opiates, reduces craving for alcohol and helps maintain abstinence. NIAAA is funding project COMBINE, a study of the potential benefits of the combined use of naltrexone and acamprosate, another promising drug, along with behavioral therapies.

One of the most tragic consequences of alcoholism is Fetal Alcohol Syndrome (FAS), the most common, preventable cause of mental retardation in the United States. If pregnant women did not drink, there would be no fetal alcohol syndrome; however, many individuals cannot stop drinking. We need to develop methods validated by research to prevent alcohol use during pregnancy. NIAAA is currently funding research to improve the identification and treatment of women who are at risk of harming their children by drinking during pregnancy.

Researchers are also involved in finding new methods of educating our children about the dangers of drinking. Recent research has shown that children who begin alcohol use at an early age are at increased risk of developing alcohol problems later. Projects are addressing methods for educating children, parents, and communities about the dangers of early alcohol use.

Alcohol abuse and alcoholism are devastating problems of national importance. Alcohol research has now reached a critical juncture, and the scientific opportunities are numerous. With the continued support of this Committee and the Congress, we are optimistic that the next few years will bring major advances in alcohol research.

RECOMMENDATION

NIAAA: The Research Society on Alcoholism requests that funding for NIAAA in fiscal year 2000 be increased by $78 million (30 percent) to $337.7 million. However, given the magnitude of the problem and the abundance of research opportunities, RSA strongly urges the Subcommittee to bring NIAAA's budget up to the level of comparable institutes. This request balances the impact of the disease, the relative underfunding of NIAAA, and the abundance of research opportunities.

NIH: For fiscal year 2000, we strongly support the funding recommendation of the Ad Hoc Group for Medical Research Funding of $18 billion for the National Institutes of Health (NIH). Sustained, stable growth in funding for the NIH is needed to build upon past scientific achievements, address present medical needs, and anticipate future health challenges. Volatility and dramatic fluctuations in funding can be as harmful to the research enterprise as inadequate growth.

PREPARED STATEMENT OF THE TEXAS NEUROFIBROMATOSIS FOUNDATION

The Texas NF Foundation is pleased to have the opportunity to submit testimony on the need for a continued Federal commitment to research on Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, brain tumors, learning dis-

abilities and heart disease affecting over 100 million Americans, as well as in support of fiscal year 2000 appropriations for the National Institutes of Health (NIH).

The Texas Neurofibromatosis Foundation was established in 1981 and is committed to meeting the needs of people challenged with NF by providing care, comfort, support, information, education, funding, and other resources for the treatment, prevention, and eventual cure of this disease. With offices in Dallas and Houston, the Foundation coordinates support groups, organizes fundraising events and educational symposiums, and assists with NF clinics across the state that serve the more than 5,000 individuals with NF in Texas. Dedicated volunteers form the heart of the organization, giving their time and talents to increase public awareness and raise the money necessary to support patient programs and research projects. Advocates from around the country look to the Texas NF Foundation as a model when establishing new a NF organization in a state. Texas is also home to some of the most exciting NF research described below.

NF, incorrectly but commonly known as elephant man disease, involves the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer and/or death. It is the most common neurological disorder caused by a single gene. While not all NF patients, like myself, suffer from the most severe symptoms, all of us live our lives with the uncertainty of not knowing whether we too will be severely affected because NF is a highly variable and progressive disease. Approximately 100,000 Americans have NF, and it appears in approximately one in every 3,500 births. It strikes worldwide, without regard to gender, race or ethnicity. There are two types of NF; type 1, which is the more common of the two and NF2 which primarily involves acoustic neuromas causing deafness and balance problems as well as other types of tumors such as schwannomas and meningiomas.

With the continued support of this Subcommittee and a relatively small Federal investment, NF has become one of the great success stories in the current revolution in molecular genetics. Because of the enormous advances that have been made, one leading NF researcher has stated that more is known about NF genetically than any other disease. Accordingly, many NF researchers believe that NF should serve as a model to study all diseases. The future promise of NF research is based upon these successes. Let me highlight for you some of the advances in NF research that have occurred since 1990:

—The discovery of the NF1 and NF2 genes and gene products;
—Determination of the close connection between NF and cancer, brain tumors, learning disabilities, heart disease, and other neurological disorders;
—Determination and understanding of the functions of the NF1 and NF2 genes and gene products including the discovery of new pathways impacted by the NF genes and gene products;
—Development of advanced animal models;
—Development of drug and gene therapies;
—Commencement of clinical trials at NCI;
—Establishment of an international consortium of NF researchers and patients;
—Rescuing learning deficits in animal models with NF1;
—Substantial increase in the number of NF researchers.

The enormous promise of NF research—and its potential to benefit tens of millions of Americans in this generation alone—has gained increased recognition from Congress and the NIH. This is evidenced by the fact that five Institutes at NIH are currently supporting NF research (NCI, NINDS, NIDCD, NICHD, and NHLBI) and NIH's total NF research portfolio has increased from $11 million in 1995 to approximately $18 million in 1998. The National Institute on Disability Research and Rehabilitation (NIDRR) within the Department of Education has also expressed an interest in pursuing NF research in the learning disability area since 35–60 percent of children with NF suffer from learning disabilities. For fiscal year 2000, the Subcommittee's continued support will be critical to build upon the basic and clinical research described below which is essential to moving us closer to a treatment and cure for this disease.

In the nine years since the discovery of the NF gene, researchers have established the connection between NF and the following diseases and disorders:

Cancer.—Dr. Samuel Broder, former Director of the National Cancer Institute, stated that NF was at the "cutting edge" of cancer research. Studies have investigated the connection between the ras oncogene, which is critical to control growth and development in healthy cells (and when mutated contributes to the formation of tumors), and the NF1 gene which is a tumor suppressor. The studies showed that ras activity can be inhibited by the NF1 protein neurofibromin. Since elevated ras activity is involved in 30 percent of all cancers, the inhibition of ras by

neurofibromin may result in a cure, not only for NF, but also for many of the most common forms of cancer.

Learning disabilities.—In addition to NF's connection to cancer, NF also provides a unique opportunity to begin to uncover a molecular basis for cognitive impairment, and it holds the prospect of possessing a radiologic marker for brain dysfunction. Specific learning disabilities are the most common neurological complication in children with NF1. The reported frequency of learning disabilities in children with NF ranges between 30 percent –65 percent. Uncovering the molecular and cellular causes for the learning deficits caused by NF should also reveal important clues on what causes and how to cure tumors in NF1 patients, because the same molecular mechanisms underlie both tumor formation and learning disabilities. For example, recent research on mice with the same mutation that causes NF1 in humans (NF1 mice) has shown that treating the mice with a drug (farnesyl transferase inhibitor) that decreases ras function (the same ras that causes cancer and tumors) CURES their learning disabilities. Studies on fruit flies have also demonstrated that the protein made by the NF1 gene is part of the c-AMP pathway, the pathway which is known to control learning and memory.

Deafness.—Leading NF researchers believe that the science has progressed to the point when a gene therapy for NF2 can be developed and tested. Unlike other genetic forms of deafness, in which mutation leads to a development or structural abnormality in the ear for which it would be difficult to envisage a treatment in the adult, NF2-associated deafness is potentially preventable or curable if tumor growth is halted before damage has been done to the adjacent nerve. NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors including schwannomas and meningiomas, as well as being a major cause of balance problems.

Heart disease.—Recently published research has also demonstrated the relationship between NF and heart disease. Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same ras which causes cancer and learning disabilities also causes heart valves to close and neurofibromin suppresses ras, thus opening up the heart valve. Errors in valve formation account for a large percentage of congenital heart disease in humans, and congenital heart disease is the most common type of congenital defect. Researchers believe that further understanding how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease. This finding opens up a new area for future research in congenital heart disease. In addition, the role of NF1 in neural tube closure suggests that NF1 research may bear on the understanding of causes of Spina Bifida, a common birth defect.

NF research is on the precipice of many major discoveries that will have broad and significant implications for Americans suffering from many disorders and diseases. For example, NCI is currently recruiting new patients for a clinical trial involving the use of farnesyl transferase inhibitors in pediatric patients with refractory solid tumors. NCI is recruiting NF1 patients with progressive inoperable neurofibromas, among others. Other areas of research opportunity include:

—Further clinical trials;
—Expansion of drug and genetic therapies for NF and related disorders;
—Further development of NF animal models;Maintenance and expansion of consortium of NF clinical researchers and patients;
—Further determination of the connection between NF and cancer, tumors, heart disease, learning disabilities, deafness, bone and other disorders;
—Further determine function of the NF genes and gene products;
—Expansion of pool of NF researchers.

This Subcommittee recognizes that our goal should be to translate the promise of scientific discovery into an improved quality of life for all Americans. To accomplish this goal, we must, as a nation, continue to invest in medical research at the NIH. Sustained, stable growth in funding for the NIH is needed to build upon past scientific achievements, address present medical needs, and anticipate future health challenges. Volatility and dramatic fluctuations in funding can be as harmful to the research enterprise as inadequate growth. Towards this end, I encourage the Subcommittee to support the recommendation of the Ad Hoc Group for Medical Research Funding, a coalition of over 200 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry, which calls for a fiscal year 2000 appropriation of $18 billion for the National Institutes of Health (NIH). In addition to providing increased funding for the NIH as a whole, this Subcommittee has recognized the promise of NF research and has included language in your fiscal year 1999 Report encouraging both NCI and NINDS to increase

their NF research portfolios through the use of: Requests for Applications, Program Announcements, the National Cooperative Drug Discovery Group Program, and Small Business Innovation Research Grants, as appropriate. I urge the Subcommittee to continue to encourage these Institutes, as well as NICHD, NIDCD, NHLBI, and NIDRR at the Department of Education to continue this trend.

In addition to continuing to provide increased funding to the NIH, I ask Members of this Subcommittee to consider that recent advances in science have shown that stem cell research may lead to meaningful treatment and cures for many debilitating and catastrophic diseases. Further, stem cell research has the potential to be applied in developing new drugs and testing them in the laboratory, so that cellular and possible adverse reactions can be foreseen and addressed prior to evaluating new drugs. We recognize that stem cell reseach brings with it important ethical and scientific oversight issues which must be considered. We support the recent ruling by the Department of Health and Human Services (DHHS) with regard to the ability of the NIH to proceed with funding stem cell research. However, we also believe that it is necessary for the NIH to establish a regulatory framework under which this scientific exploration should be undertaken to ensure that the social and ethical issues are carefully considered.

In closing, I would like to end with a statement that appeared in an edition of Cold Spring Harbor Laboratory's newsletter which focused on major breakthroughs in NF research: "the hope is that the day may come when doctors can flip critical switches to repair the broken circuits in each of these disorders and diseases. Such life-changing therapies will be the reward for years of enthusiastic basic research." I believe that with your continued support of this Subcommittee and Congress, that day will soon be here.

PREPARED STATEMENT OF THE NYU SCHOOL OF MEDICINE

The NYU School of Medicine is pleased to have this opportunity to submit testimony in support of fiscal year 2000 funding for the National Institutes of Health (NIH) as well as to discuss a few of the exciting initiatives underway at the School of Medicine.

In my opinion, there has never been a more exciting time to enter medicine. Enormous breakthroughs have allowed great advances in our understanding of disease and our ability to devise new therapies. And we know with certainty that this explosion of knowledge will continue. With continued federal support for basic, cutting edge research supported through the NIH, we will continue to move closer to our goal of translating the promise of scientific discovery into an improved quality of life for all Americans.

The NYU School of Medicine takes pride in a history that goes back to 1837 and includes initiation of and participation in many of the major events in American medicine through two centuries. The School annually graduates 150 physicians, and it employs 3,000 individuals including more than 800 faculty members. For 150 years the School has provided high quality patient medical services and medical supervision to Bellevue Hospital Center, New York City's premiere municipal hospital. The mission of the School is threefold: the training of physicians, the search for new knowledge, and the care of the sick. These three missions must be carried out simultaneously for they are wholly dependent upon each other, not only for inspiration, but for their very means of success. At the School of Medicine, we recognize that in order to excel in these three missions, we must be responsive to the major events and trends that are shaping medicine in our time. These include: the revolution in molecular biology and medical technology; the societal imperatives imposed by rising health care expectations and finite limits on resources; the explosive growth in biomedical information; and the increasing role of the patient in the decision-making process. Following the recent alliance of New York University's hospitals with the Mount Sinai Medical Center, the School is now poised to enter a period of unprecedented growth in the area of medical and scientific research.

I would like to highlight three exciting initiatives underway and under development at the School of Medicine. These initiatives provide a snapshot of our commitment to providing a unique atmosphere of public service, the highest quality medical care for the underserved, research and education. The School of Medicine is developing a comprehensive Program in Women's Cancer (PWC). This program will be an integral component of the Kaplan Comprehensive Cancer Center (KCCC). The PWC will encompass the full spectrum of clinical services, advanced training, fundamental and translational research into those cancers that exclusively or primarily affect the female reproductive tract, with a focus on minority women. The components of this program include: etiology and biology; risk identification and preven-

tion; screening; diagnosis and treatment; palliation and rehabilitation; and psychosocial support. The School is seeking the Subcommittee's support to expand its PWC.

A second key component of the KCCC is its research in the area of the environmental causes of cancer. The KCCC is one of the few comprehensive cancer centers with a strong component in this area. Research focuses on understanding the roles of environmental risk factors and their joint action with genetic or biochemical factors in disease etiology, specifically cancer. The School is seeking the Subcommittee's support to expand research in this area for: studies on the development and validation of new biomarkers of exposure, effect and susceptibility, which will aid in assessing the health risks associated with exposure to hazardous substances; studies to identify, evaluate, or validate factors in an individual's environment or physiological makeup that may lead to an increased likelihood of cancer relative to the general population; studies on the etiology of cancer.

The School is also working with the Stephen Hassenfeld Children's Center to launch a model integrated and comprehensive treatment program for children with cancer and their families generally, but with an additional emphasis on the singular needs of children with brain tumors that focuses on improving their quality of life for long term survival. Brain tumors represent the second major cause of cancer in children in North America and Europe and, because of the poor results of treatment generally, are the leading cause of cancer-related death in children and adolescents. Current estimate suggest that there will be 200,000 pediatric cancer survivors by the turn of the century, yet currently there are few comprehensive care programs that support children and families over the long term, and none that serve a large economically disadvantaged population. Over 40 percent of the Center's patients last year were under-represented minorities, and more than half were uninsured or insured through Medicaid.

The program at the Hassenfeld Center will connect access to specialty care to social services, including counseling and access to a psychogeneticist for children with brain tumors. School-related problems are four times more frequent in pediatric cancer patients than in healthy children, and often include specific learning disabilities with underlying deficits in essential cognitive processing systems that limit the survivor's ultimate educational attainment and vocational level. This program will address the goals of the minority health initiative within the Department of Health and Human Services which aims to reduce the burden of disease in racial and ethnic minority groups, and the School is seeking the Subcommittee's support for this demonstration program which will serve as a national model for providing comprehensive care to children with brain tumors.

This Subcommittee has been a leader in ensuring that we continue to adequately invest in medical research, and on behalf of the School I thank you for your continued support for the National Institutes of Health. For fiscal year 2000, the NYU School of Medicine supports the funding recommendation of the Ad Hoc Group for Medical Research Funding, a coalition of nearly 200 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry, which call for an appropriation of $18 billion for the NIH. Sustained, stable growth of funding for the NIH is needed to build upon past scientific advances, address present medical needs, and anticipate future health challenges. Volatility and dramatic fluctuations in funding can be as harmful to the research enterprise as inadequate growth.

Recent advances in science have established that the potential to push the frontier of stem cell research may lead to meaningful treatment and cures for many debilitating diseases. The School of Medicine is involved in cutting edge research supported by the NIH involving the use of stem cells and believes that the potential application of knowledge gained from this research has the potential to reduce human suffering. Further, stem cell research has the potential to be applied in developing new drugs and testing these drugs in the laboratory, so that cellular and possible adverse reactions can be foreseen and addressed prior to evaluating new drugs. We recognize, however, that important ethical and scientific oversight issues accompany this research which must also be considered. The School of Medicine supports the recent ruling by the Department of Health and Human Services (DHHS) with states that the NIH may continue to fund stem cell research. However, we believe that it is vitally important for the NIH to establish a regulatory framework under which this scientific exploration can be undertaken to ensure that the social and ethical issues are carefully considered. The scientific community looks toward the National Bioethics Commission (NBAC) to provide the ethical framework for proceeding with this important field of science. Further, it is important that stem cell research be conducted under public scrutiny rather than occur elsewhere in an unregulated, secretive environment.

PREPARED STATEMENT OF GILBERT S. OMENN, M.D., PH.D., EXECUTIVE VICE PRESIDENT FOR MEDICAL AFFAIRS, UNIVERSITY OF MICHIGAN, AND CEO, UNIVERSITY OF MICHIGAN HEALTH SYSTEM

I am Dr. Gil Omenn, Executive Vice President for Medical Affairs of the University of Michigan and CEO of the University of Michigan Health System. I am an internist and a geneticist, as well as a former Associate Director of OSTP and of OMB.

I am submitting my comments on behalf of a coalition of over 20 academic health centers across the nation to highlight issues of concern to all academic health centers in the United States. The recommendations which I will present have been endorsed in various parts by the Association of American Medical Colleges (AAMC) and the Federation of American Societies for Experimental Biology (FASEB).

First, I want to thank Chairman Specter and the Members of the Senate Labor/HHS/Education Subcommittee for your continuing leadership in providing significant increases in appropriations for the National Institutes of Health over the past several years. Your support has allowed the agency to greatly expand the nation's medical research enterprise to investigate the causes, prevention, and treatment of the many healthy problems which affect people throughout the country and around the world. The $2 billion increase which you provided for fiscal year 1999 is a splendid launch toward the bipartisan goal of doubling the NIH budget by 2003.

We must remember that our country now spends more than $1 trillion on medical care, as we think about the size of the NIH appropriation. I estimate that 20–30 percent of that annual figure, a very large sum, is spent chasing the symptoms of common diseases—most cancers, neurologic diseases, psychiatric disorders, gastrointestinal disturbances, arthritis of various kinds, and others—for which we simply do not yet know enough about the underlying causes and the disease pathways to intervene to prevent, reverse, or modify the complications for our patients. No way do we or the American people want to be stuck with such limited basis for medical care and public health.

I am contacting you to seek your help in further strengthening the extraordinary partnership that was established with great foresight years ago between academic institutions and the federal government. This partnership has spawned remarkable scientific developments over decades. These advances position us—academia, industry, and the government—to work together to exploit the golden era of biology. Academic institutions across the nation are proud to be major players in this partnership.

We in the academic health community urge you to improve this academic/federal partnership by recognizing the following three problems which limit the extramural biomedical and behavioral research community from operating at optimal capacity and efficiency:

(1) the need for state-of-the-art facilities to carry out the increasing volume of federally-supported biomedical and behavioral research;

(2) the need for competitive salaries for extramural researchers;

(3) the need for a peer-reviewed, flexible grant program for shared resources to meet evolving and transitional research needs at the institutional level.

INCREASE FUNDING FOR FACILITIES—CONSTRUCTION, RENOVATION, EQUIPMENT

Exciting developments in genomics, chemical biology, neurosciences, cancer, and many other fields require new kinds of equipment and facilities. Even the best minds cannot compensate for outdated equipment and facilities. It is vitally important that we have the facilities and equipment to fully exploit research opportunities and utilize the increased project grant funding.

The National Science Foundation (NSF) completed a study in 1998 on the status of scientific research facilities at U.S. colleges and universities. This analysis generated an estimate of $3.6 billion in deferred biomedical research construction and repair or renovation projects. In a March 1998 report, the Association of American Medical College (AAMC) stated that "The government should reestablish and fund an NIH construction authority, consistent with the general recommendations of the Wyngaarden Committee report of 1988, which projected at that time the need for a 10-year spending plan of $5 billion for new facilities and renovation." In June 1998, the Federation of American Societies of Experimental Biology (FASEB) reported that "Laboratories must be built and equipped for the science of the 21st Century. Infrastructure investments should include renovation of existing space as well as new construction, where appropriate."

My colleagues and I urge you to provide the NIH with $250 million for extramural facilities construction in the fiscal year 2000 Labor/HHS/Education funding bill. The

funds would be awarded on a competitive basis, requiring institutional matching to leverage the NIH resources.

RAISE THE SALARY CAP ON EXTRAMURAL SCIENTISTS

NIH and the academic community share a major concern about recruiting and retaining excellent clinician-investigators in biomedical and behavioral research. These physicians typically have considerable accumulated debt from their medical and post-graduate training, and they have an opportunity cost in choosing research careers. The med schools increasingly expect them to earn their way through clinical service and, of course, by earning support for their research time by competing for federal grants. As they move up the ranks and develop successful careers, they or their academic departments are penalized by a salary rate cap imposed in 1991. Unfortunately and perhaps unintentionally, Congress omitted a salary adjustment to account for inflation. Thus, the maximum salary rate (on a 100 percent basis, prorated for the proportion of time spent in funded research) was $125,000 from 1991 through 1998. In the fiscal year 1999 budget, Congress did adopt the principle of increasing the cap by nudging it upward to $125,900.

For its intramural program, the NIH has created new mechanisms to keep talented intramural scientists on the NIH campus: the Senior Biomedical Research Service (SBRS). Under this system, NIH can pay senior investigators salaries up to $151,000 a year. This amount is roughly equal to what the salary cap on academic researchers would be if it had been indexed for inflationary increases over the past decade.

In order to attract and retain the most talented individuals to biomedical and behavioral research, especially clinician-investigators, and in order to assure equity between intramural and extramural scientists, we seek your support in raising the current salary maximum paid to extramural academic researchers to match the maximum salary level which the NIH can pay its own senior scientists under the Senior Biomedical Research Service. The adjustment could be phased in over two years to smooth the funding transition.

A FLEXIBLE INSTITUTIONAL RESEARCH FUND TO ENHANCE THE EFFICIENCY OF RESEARCH

A third concern to our nation's academic medical institutions is inefficiency in the federal-academic partnership. As you know, during the past decade, financial pressures on the clinical enterprise of academic medical centers have intensified, particularly so since the implementation of the Balanced Budget Act of 1997 during the past year. It is increasingly difficult to generate institutional margins to underwrite research needs that are not covered well in the project grant mechanism.

We want to enhance the impact of NIH funding by being flexible enough to change with the science, accommodate changing national priorities, and make the most of the NIH and institutional investments in individuals throughout their careers. Glitches in funding cycles, changes in NIH policies and priorities, needs for research resources, and opportunities to mobilize research in new directions could be addressed better with a modest fund in the hands of the institutional leaders, based on competitive funding. Collaborative, interdisciplinary research initiatives can be stimulated through resources at a level above the individual investigators.

Thus, we propose that you provide funding for NIH to establish a "Flexible Institutional Support for Health Research" or "FISHR" program. Program resources would provide institutional support for the following priorities: to fund interdisciplinary, shared research resources; to assist postdoctoral fellows and beginning investigators to establish independent research projects; and to rapidly infuse short-term resources into investigations which offer tremendous promise for research progress.

We recommend that the NIH establish such a peer-reviewed, three-year grant program through the National Center for Research Resources. Grants could be in the range of $25,000 to $300,000 per year for Deans of medical, public health, nursing, dental, and pharmacy schools which qualify through having NIH project awards.

Applications would provide general plans for needs anticipated to evolve. Awards would permit flexibility within the institution to determine spending priorities, within the categories approved (as proposed above). To assure accountability, we suggest two mechanisms: a local internal review committee, comprised of NIH-supported investigators at the institution, to review specific proposed allocations, on a prospective basis; then a retrospective review by NIH research program staff prior to approving eligibility to submit a competitive renewal application at the end of the grant award period.

We urge you to include in the fiscal year 2000 appropriation for NIH $60 million to initiate this Flexible Institutional Support for Health Research (FISHR) Program. Such annual funding would favorably modify the impact of the recent stresses experienced by research and academic institutions which threaten the efficiency of our national research enterprise.

CONCLUDING REMARKS

Mr. Chairman, the extramural research community applauds your efforts to increase funding for biomedical and behavioral research through to NIH. Based on polls conducted by Research!America, including polls in my state of Michigan, we know that the American public strongly supports these investments and has high expectations for payoff in new knowledge and medical and public health innovations.

We are confident that the Congress and the NIH can enhance the impact of the project-based investments by taking the three additional steps we recommend: increase to $250 million in fiscal year 2000 the funding to upgrade extramural laboratory space and instrumentation; increase the maximal salary rate on NIH grants to match the maximum for intramural scientists; and initiate a Program for Flexible Institutional Support for Health Research (FISHR). Each of these steps will increase the productivity and efficiency of the academic/government partnership in biomedical and behavioral research and research training.

On behalf of academic health centers across the nation, I thank you for your attention to these needs and recommendations. Best wishes to each of you.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Specter, members of the Subcommittee, thank you for this opportunity to present written testimony on behalf of Rotary International in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention. Rotary International is a global association of more than 29,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in 160 countries. In the United States today there are some 7,500 Rotary clubs with 400,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding.

In the United States, Rotary has formed the USA Coalition for the Eradication of Polio, a group of committed child health advocates which includes Rotary, the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, and the U.S. Committee for UNICEF. These organizations join us in expressing our gratitude to you for your staunch support of the international program to eradicate polio. Over the past several years, you have steadily increased your appropriation for the polio eradication activities of the Centers for Disease Control, and for fiscal year 1999 you appropriated a total of $67 million for the CDC's overseas polio eradication efforts. This investment has made the United States the leader among donor nations in the drive to eradicate this crippling disease. The target year is 2000 for eradication, with certification by 2005.

Fewer than two years remain to defeat this disease in the nations where the polio virus still causes death and disability. With your continued support, soon no child will ever be struck down by polio again.

FISCAL YEAR 2000 BUDGET REQUEST

For fiscal year 2000, we respectfully request that you provide $83.4 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention, thereby meeting the President's budget request. This increase of nearly $17 million over the fiscal year 1999 funding level is needed to meet the enormous costs of eradicating polio in its final stronghold—sub-Saharan Africa. The underdeveloped and conflict-torn countries of Africa represent the greatest challenges to the success of the global Polio Eradication Initiative. This additional appropriation will allow the CDC to help African nations accelerate polio eradication activities, improve surveillance for polio and other diseases, and support peace-building ceasefires for NIDs. Without additional commitments, we may not be able to eradicate polio in Africa by the Target 2000 date, prolonging the need to continue expensive NIDs and routine immunization world-wide. The time for the final assault against polio is now.

Humankind is on the threshold of victory against polio, and we must not miss this window of opportunity. Poliomyelitis will be the second major disease in history to

be eradicated. The world celebrated the eradication of smallpox in 1979, and no child anywhere in the world will ever suffer from smallpox again. It is estimated that today as many as 20 million people around the world are living with paralysis from polio. The eradication of polio, achieved through your leadership, will not only save lives and suffering, but will also save our country's financial resources.

ERADICATING POLIO WILL SAVE THE UNITED STATES AT LEAST $230 MILLION ANNUALLY

Last year the Chairman of the House Committee on International Relations commissioned the General Accounting Office to investigate the soundness of WHO cost estimates for the eradication or elimination of seven infectious diseases. The United States was a major force behind the successful eradication of the smallpox virus, and the GAO concluded that the eradication of smallpox has saved the United States some $17 billion to date. Even greater benefits will result from the eradication of polio.

Although polio-free since 1979, the United States currently spends at least $230 million annually to protect its newborns against the threat of importation of the polio virus, in addition to its investment in international polio eradication. Globally, over 1.5 billion US dollars are spent annually to immunize children against polio. This figure does not even include the cost of treatment and rehabilitation of polio victims, nor the immeasurable toll in human suffering which polio exacts from its victims and their families. Once polio is eradicated and immunization against it can be discontinued, tremendous resources will be unfettered to focus on other health priorities.

PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Thanks to your appropriations, the international effort to eradicate polio has made tremendous progress during the past two years.

—The global eradication strategy is working. In 1985, when Rotary began its PolioPlus Program, 100 nations around the world suffered under the burden of polio. The Western Hemisphere has now been polio-free for nearly 8 years, and today polio is confined only to Sub-Saharan Africa, parts of the Middle East, and South Asia. Five of the six most populous countries in the world are now polio-free.

—Some seventy-five countries conducted NIDs in 1998, immunizing over 450 million children against polio—nearly 75 percent of the world's children under the age of five.

—For 1998, the World Health Organization now expects that some 6,000 polio cases will be reported. While this is an increase over the 1997 number, in fact it is a positive indication of great improvements in the ability to detect polio cases.

—During its third year of NIDs, India was able to immunize over 130 million children on one day—the largest public health event in history. Pakistan, Bangladesh, and other neighboring countries coordinated their NIDs with India's to achieve the maximum effect over the entire region. India has agreed to undertake extra rounds of NIDs in 1999 in order to accelerate the drive to eradicate polio by the target date.

—Despite economic difficulties and civil conflict, more than 40 African countries conducted National or Sub-National Immunization Days during 1997/1998, as part of the continent-wide "Kick Polio Out of Africa" campaign championed by South African President Nelson Mandela, reaching nearly 70 million children. Polio-free zones are emerging in both Northern and Southern Africa.

—With the help of the world community, all remaining polio-endemic nations, including those in the midst of severe civil conflict, have now started down the path to polio eradication by undertaking NIDs or Sub-National Immunization Days.

—The three-year "Operation MECACAR" (Middle East, Caucasus, Central Asian Republics) immunization campaign has been deemed a success, virtually eliminating polio from 19 contiguous countries stretching from the Middle East to Russia. For 1998, polio cases reported from WHO's European region have been confined to Southeastern Turkey.

—China has reported no laboratory-confirmed indigenous polio cases for three years, and the last case of polio in the entire Western Pacific was detected in Cambodia in March 1997. We and our partners believe that the Western Pacific can be certified polio-free early in the year 2000.

THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Rotary commends the CDC for its leadership in the global polio eradication effort, and greatly appreciates your Subcommittee's support of the CDC's polio eradication activities. For 1999, you appropriated a total of $67.2 million for the CDC's global polio eradication activities, which included $20 million in the Public Health and Social Services Emergency Fund. Because of Congress' unprecedented support, in 1999 the CDC is:

—Supporting the international assignment of more than 70 long-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies.

—Providing over $35 million to UNICEF for approximately 400 million doses of polio vaccine and operational costs for NIDs in some 60 countries in Asia, Eastern Europe, the Middle East and Africa. Many of these NIDs would not take place without the assurance of the CDC's support.

—Providing over $10 million to WHO for surveillance and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance has emerged as a critical need, to determine where polio cases are continuing to occur.

—Helping to support countries such as Afghanistan, Angola, D.R. Congo, Liberia, Nigeria, Sierra Leone, Somalia and Sudan in planning and conducting NIDs despite ongoing civil conflict. The CDC's logistical support was critical to the success of Liberia's first-ever NIDs earlier this year. In the Democratic Republic of the Congo, the only populous polio-endemic country which has not conducted full NIDs, warring factions have now agreed to "days of tranquillity" in order to allow immunization campaigns to take place in July and August.

—With the additional $17 million increase in polio eradication funds in the President's fiscal year 2000 budget request, the CDC would be able to provide an additional $8 million for polio vaccine for use in extra rounds of NIDs and mopping-up activities during the intensification phase, an additional $5 million to WHO to support surveillance, and an additional $4 million for laboratory support and expansion of field staff.

OTHER BENEFITS OF POLIO ERADICATION

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases. Already, much of Latin America is free of measles, due in part to improvements in the public health infrastructure implemented during the war on polio. As a result of this success, measles has been targeted for eradication in the Americas by the year 2000. The disease surveillance system—the network of laboratories and trained personnel built up during the Polio Eradication Initiative—is now being used to track measles, Chagas, neonatal tetanus, and other deadly infectious diseases. NIDs have been used as an opportunity to give children essential vitamin A, as well as polio vaccine. The campaign to eliminate polio from communities has led to increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and distribution, and the logistics of organizing nation-wide health programs. Lastly, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives.

RESOURCES NEEDED TO FINISH THE JOB OF POLIO ERADICATION

The World Health Organization now estimates that approximately $890 million in external funds is needed to help polio-endemic countries carry out the polio eradication strategy during the critical years 1999–2001. The estimated shortfall for the three years 1999–2001 now stands at nearly $370 million. In the Americas, some 80 percent of the cost of polio eradication efforts were borne by the national governments themselves. However, as the battle against polio is taken to the poorest, least-developed nations on earth, and those in the midst of civil conflict, many of the remaining polio-endemic nations can contribute only a small percentage of the needed funds. In some countries, up to 100 percent of the NID and other polio eradication costs must be met by external donor sources. We are asking that the United States continue to take the leadership role in meeting this shortfall.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Belgium, Canada, Germany, Finland, Italy, and Norway are among those countries which have followed America's lead and have re-

cently announced special grants for the global Polio Eradication Initiative. Japan and Australia are major donors in Asia and the Western Pacific, and Japan has also expanded its support to polio eradication efforts in Africa. Denmark, Germany and the United Kingdom have made major grants that will help India eradicate polio by the target year 2000. In addition, last summer U.K. Prime Minister Tony Blair announced a grant of U.S. $30 million to ensure that Kenya, Tanzania, and Uganda also meet the eradication goal.

By the time polio has been eradicated, Rotary International expects to have expended approximately $500 million on the effort—the largest private contribution to a public health initiative ever. Of this, $334 million has already been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 120 countries. Over the past 18 months, realizing the increased role which external donors need to play in order to ensure that polio eradication is not jeopardized due to lack of resources, The Rotary Foundation has committed an additional $40 million to its PolioPlus Fund. More importantly, we have mobilized tens of thousands of Rotarians to work together with their national ministries of health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities.

Polio eradication is an investment, but few investments are as risk-free or can guarantee such an immense return. The world will begin to "break even" on its investment in polio eradication only two years after the virus has been vanquished. The financial and humanitarian benefits of polio eradication will accrue forever. This will be our gift to the children of the twenty-first century. Thank you for this opportunity to present written testimony.

Prepared Statement of Richard J. Boxer, Board of Directors, Lymphoma Research Foundation of America

Chairman Specter and Members of the Subcommittee: Thank you for the opportunity to present written testimony to you on behalf of the Lymphoma Research Foundation of America, LRFA, and more importantly, the over 600,000 American men, women, and children who are living with the diagnosis of lymphoid cancers (Hodgkin's and non-Hodgkin's lymphoma, chronic and acute lymphocytic leukemia), and the millions who have died of these diseases or will be diagnosed in the future. We believe it is critical for this Committee to support the basic research and clinical trials that one day will allow us to speak about lymphomas in the past tense. Your support will place this dreaded disease in the history books alongside polio, smallpox, and other conquered health problems.

I am on the Board of Directors of the Lymphoma Research Foundation of America, the nation's largest organization dedicated to providing comprehensive information and support to lymphoma patients, their families, and friends. The Lymphoma Research Foundation of America also finances research into better and safer treatments for those patients with a lymphoma. By the summer of 1999 seventy-two research projects totaling nearly two and a half million dollars will have been funded by our organization. In addition to research, LRFA spearheads National Lymphoma Awareness Week, and also provides a comprehensive slate of educational and support programs, which includes: a quarterly newsletter, a buddy program, clinical trials information, physician referrals, and educational forums. But more importantly than the money we have raised, we have raised hope for those with the disease.

I did not choose to be here today. My family and I would have done anything to avoid me testifying about lymphomas. But the disease chose me to be here. I am one of the fortunate victims of the disease, for I have been cured. I was diagnosed with non-Hodgkin's lymphoma in November 1995 and underwent the removal of my spleen and a portion of my pancreas, seven courses of chemotherapy, and a bone marrow transplant in the successful treatment of my cancer. It has taken a tremendous toll upon my life and my family's life, and taught me about the other side of health care, for I had been treating cancer for 25 years before I was one of its victims.

One out of every two American men and one out of every three American women will develop cancer in their lifetime. As a urologist who had been treating prostate, kidney, bladder, and testicular cancers for 25 years, the severe effects upon my patients and their families were constant, yet objective and distant parts of my life. When I developed cancer, suddenly I was wearing the mortifying fear and anguish that I had seen wrap the faces of my patients. I was now a statistic, not a provider.

I was searching for the finest treatment, and worrying whether my health insurance carrier would cover the expenses. I was facing the disability of a prolonged ill-

ness, and wondering how my business and home expenses were going to be paid. I experienced the cold objectivity and the warm humanism of my health providers. I experienced the doubts about the therapeutic choices and the lack of knowledge about the outcomes. I endured the pain of surgery, the life-draining chemotherapy, a bone marrow transplant. I was the recipient of the profound benefits of the research and clinical trials that has lifted the darkness of the unknown and provided me with a chance to be cured. I live because of those patients who came before me and the research performed by scientists. What I learned, I now share with my patients and colleagues with the intent that I have gone through my experience for a reason.

The statistics about lymphomas are staggering:

1. The incidence of lymphomas is rising faster than all but one other cancer in America
2. More than 600,000 Americans are living with the diagnosis of a lymphoma
3. It is the fourth leading cause of death by cancer of men 25–60 years old
4. It is the fifth leading cause of death by cancer in women 25–60 years old
5. Sixty percent of childhood cancers are lymphomas or related diseases (leukemia)
6. More than 88,600 Americans will be stricken by lymphoid cancers in 1999
7. The incidence of Non-Hodgkin's lymphoma has risen by 85 percent since the early 1970's
8. Fifty percent of those diagnosed with lymphoid cancers will die of the disease
9. Lymphoid cancers represent 7.3 percent of all cancers diagnosed in America
10. Lymphoid cancers, which kill in the prime of life, represent 8.8 percent of cancer deaths
11. Lymphoma research represents just 2.4 percent of the National Cancer Institutes' budget
12. Although there have been advances in the basic knowledge and treatments of lymphoid cancers, there has been a continued rise in the incidence and the human suffering of the diseases.

I carry a message of hope, for I am the embodiment of hopes and dreams of anyone who has or will have a lymphoma—I have been cured as a result of the art and science of medical research in large part funded through the generosity of the American people and because of the leadership of the Congress.

I carry a message of fear, for I was struck down, but not out, by an insidious disease. And it could happen to anyone. It could happen to you or your loved ones. There is also the fear of the unknown: What effects and damage will the massive and debilitating chemotherapy visit upon the "cured" patient in the future?

I carry a message of urgency, for there will be over 88,600 Americans diagnosed with lymphoid cancers in 1999, and half will die due to the disease. These chilling statistics will continue until an answer is found. You have the power and responsibility to provide the courage and leadership to increase the funding that will eventually lead to the discovery of the cure, and prevention of lymphoid cancers.

Last year, Congress took the courageous step of declaring its desire to double the NIH budget by 2003. The fifteen percent "down payment" that was appropriated last year sent a significant message to the nation, and particularly the research community that Congress was very committed to the eradication of cancer. The Lymphoma Research Foundation of America strongly endorses the Ad Hoc Group of Medical Research Funding for a doubling of the budget of the National Institutes of Health over the next five years.

By increasing the budget now, and therefore bringing closer the time when lymphoid malignancies are prevented and cured, the Congress is acting fiscally responsible for the future. Certainly, an ounce of prevention is worth a pound of cure. By investing now, you will save billions of dollars in the future, for the nation will not be burdened with the expense of caring for the victims of lymphoid cancers. This investment will not only save dollars, it will save hundreds of thousands of Americans the misery of the disease and the death caused by it.

Specifically, the Lymphoma Research Foundation of America requests that the Subcommittee include in its Fiscal 2000 Committee Report language calling for:

1. Increase appropriations for lymphoma research at the National Cancer Institute.
2. Promote new innovative research models based upon collaborative methods to maximize current lymphoma research funded by the National Cancer Institute.
3. Promote research into the currently incurable low-grade and aggressive lymphomas
4. Coordinate research efforts with the National Institute of Environmental Health Sciences (NIEHS) and the Centers for Disease Control (CDC) to explore the environmental and other factors responsible for lymphomas.

Just as the courageous American soldiers fought on the front lines of battlefields to preserve our freedoms from assault by a foreign enemy, and the scientists labored to give them the most modern weapons with which to fight, all funded by past Appropriations Committees, the front line doctors and research scientists rely upon the members of this Subcommittee to fund a battle that has claimed more lives than all the wars this country has ever fought. The enemy is different, but no less deadly. When will we join together, Democrats and Republicans, and declare that enough is enough? When do our priorities change to increase our focus on the most basic fundamental needs of all Americans—the freedom from cancer?

In the name of the tens of thousands of men, women, and children who will be stricken with lymphoid cancers, strike back. Strike a blow against this killer. Increase the funding of the National Institutes of Health and specifically the National Cancer Institute, and express concern over the rapidly rising incidence of lymphoid cancers.

Thank you for the opportunity to present written testimony for the record.

PREPARED STATEMENT OF JOAN I. SAMUELSON, J.D., PRESIDENT, PARKINSON'S ACTION NETWORK

The Parkinson's Action Network was created in 1991 to give voice to a community that has been largely invisible, and to increase funding for Parkinson's research in an effort to speed research, deliver breakthroughs and cure this dreadful disease.

I am one of a million Americans who suffer with Parkinson's disease. Parkinson's is a devastating progressive neurological disease that makes it difficult to walk, causes uncontrollable tremors, and in its final states robs individuals of the ability to speak or move. It is caused by the degeneration of brain cells that produce dopamine, a neurochemical controlling motor function

Contrary to popular myth, Parkinson's is not a disease that affects only the elderly. I was diagnosed at 36. Michael J. Fox was in his early 30s. In fact, the average age of onset is 57, with one third of all victims' symptoms starting in their 20s, 30s and 40s. The prognosis for Parkinson's patients is a grim one: more than a third lose their jobs within one year of diagnosis; daily functioning becomes increasing difficult; treatments become ineffective, or cause complicated side-effect. The battle against loss of function is ongoing, expensive and in the end a losing one.

Conventional treatment for Parkinson's is a 30-year old drug commonly known as "L-dopa" which tries to replace the missing dopamine with an artificial substitute. It usually restores function to a certain extent and at first may seem like a miracle drug. But it works inefficiently, produces side effects, and eventually does not work at all. As the dopamine cell degeneration advances, we lose the automatic movements needed to walk, talk, swallow—eventually becoming unable to move at all.

I am one of the fortunate ones who, despite my disability, can still participate in society enough to appear before you and share this story. With each passing month, however, I see the day approaching when that will not be possible.

I am here today because my life—and the life of all Parkinson's patients—depends on it. Without a more rigorous commitment to funding Parkinson's research the promise of better more effective treatments—or finding a cure altogether—will remain beyond the reach of my generation, and perhaps generations to come.

This need not happen. Research on Parkinson's disease is at a major crossroads, with important new scientific opportunities for a quantum leap in treatments for Parkinson's and related disorders. In fact, leading scientists identify Parkinson's as the neurological disorder most likely to produce a breakthrough therapy and/or cure. To reach that point, however, there are several areas needing a more aggressive research investment:

—*Epidemiological and Environmental Research*.—A major new finding has narrowed the cause of classic Parkinson's, eliminated inherited genetic factors, and points to outside "triggers" such as environmental toxins that result in dopamine cell death and Parkinson's symptoms.

—*Brain Repair*.—Parkinson's-focused research, applying current basic scientific findings to development of an effective reversal of Parkinson's effects, is driving this new neuroscientific field. With Neural Growth Factors, researchers are identifying a growing number of proteins that function to nurture nerve cells, and even appear to restore life to "dead" tissues. With Neural Cell Transplantation, researchers have implanted neural tissue into the degenerated area of the brain and proven that the new cells can thrive and renew production of dopamine. And Cell Line Development research is discovering several ways that a sufficient supply of cells can be made available.

—*Increased Understanding of Disease Process*.—Scientists are increasing their insights of the Parkinson's disease process in which the cells appear to self-destruct after assaults from one or more causative factors, particularly environmental factors.

—*Role of Genetics*.—Recent discoveries have advanced our understanding of the role of genetics in Parkinson's, bringing about new clues about the disease process. A widely cited 1997 discovery of the alpha-synuclein gene did not produce a causal gene per se, but is a major clue in the matrix of understanding Parkinson's. Moreover, the finding eliminating a genetic role in classic Parkinson's has also found one in "young onset" cases like mine, when symptom onset occurs before age 50.

These discoveries, however, are coming in slow motion. Scientists in the field describe immense frustration with the halting pace of research breakthroughs because of inadequate funding for Parkinson's research. They tell us there is a correlation between an investment in research and improved treatments or finding a cure. But first, the funds must be found, and spent. Funding for Research on Parkinson's and Related Disorders

When Congress passed the Morris K. Udall Parkinson's Research Act in 1997 the Parkinson's community believed the time for investing in Parkinson's research had finally come. This landmark legislation authorized $100 million in research at the National Institutes of Health for research focused on Parkinson's disease.

NIH, however, has not fulfilled the promise of the Udall Act. In fact, they have misrepresented the amount of funding being spent on Parkinson's research—short changing those who suffer every day with this dreadful disease and undermining Congressional intent.

Last year, the Parkinson's Action Network assisted Congressman Fred Upton—lead House sponsor of the Udall Act—in examining how much of the fiscal year 1997 funding the NIH counted as "Parkinson's research" was actually being spent on Parkinson's focused research as required by the Udall Act. NIH reported to the Congress that 40 percent of its funding went to "direct" research on Parkinson's and 60 percent funded "related" research.

Congressman Upton obtained from NIH a list of Parkinson's research grants for fiscal year 1997 totaling $89.2 million. We then collected abstracts for each of the grants and distributed them to 8 independent evaluators—all of whom conduct research with a focus on Parkinson's disease and related disorders—at some of the most prestigious medical schools or biomedical facilities across the country. They each hold M.D. and/or PhD. degrees with specialties in the fields of neurology, basic neuroscience, neuropathology, neuropharmacology, or neurotoxicology. Six of the evaluators were chairs of their departments and all had experience with the NIH extramural grant system as grant recipients. The majority also serve as members of NIH peer review study sections.

The evaluators received 373 grant abstracts and were asked to review the grants and assign them to one of three categories: "focused," in which the principal focus of the research is the cause, pathogenesis, and/or potential therapies or treatments for Parkinson's disease; "related," in which the research is likely to have some benefit in finding the cause, pathogenesis, and/or potential therapies or treatments for Parkinson's disease, although that is not the principal focus of the research project; or "non-related" research, in which the research is unlikely to have residual or direct benefit to finding the cause, pathogenesis, and/or potential therapies or treatments for Parkinson's disease.

What our evaluators found was shocking: close to 40 percent ($34 million) of the funding dollars NIH purported to spend on Parkinson's disease did not support Parkinson's research at all. In all, the evaluators found that 149 of the 373 grants were "unrelated" and unlikely to have a direct OR residual benefit to finding the cause, pathogenesis, and/or potential therapies or treatments for Parkinson's.

Included in this list were grants focused on other diseases, including Alzheimer's, Huntington's, drug abuse, even AIDS, as well as work at the National Institute of Diabetes and Digestive Diseases. As one scientist put it, "it appeared that any neurodegenerative disease was included. This is like trying to figure out how the motor of a car works by studying the muffler. They are both parts of the same car, but understanding exhaust helps little in the understanding of the motor."

The study also found that only about one-third (34 percent) of the research was clearly dedicated to Parkinson's focused research. That means that for fiscal year 1997, the NIH spent only $31.5 million on research that is likely to have a direct benefit to finding the cause, pathogenesis, and/or potential therapies or treatments. This falls far short of the promise of the Udall Act.

At best, the evaluators found that an additional 27 percent (or $24 million) of the funding was related research—research that was likely to have some indirect ben-

efit in finding the cause, pathogenesis, and/or potential therapies or treatments for Parkinson's disease.

For fiscal year 1999, the NIH says they will spend $106 million on Parkinson's research. What part of that will be totally unrelated to Parkinson's? What small part may actually lead to understanding the disease, finding a cure, and improving treatment and the quality of life of individuals suffering with Parkinson's?

Far too little we fear.

The Parkinson's Action Network believes that Congress must act to ensure that NIH lives up to the statutory requirements Congress established when it unanimously adopted the Udall Act in honor of its colleague in 1997. It is too late to help Mo Udall, but it is not too late to honor his memory and help an entire generation by speeding the way to new breakthroughs. The Network urges the Committee to direct NIH to meet its obligations under the Udall Act and fund at least $100 million on "research focused on Parkinson's disease." Without such a directive we feel certain that funding for Parkinson's focused research will fall far short. It will be far short of what is required by law. It will be far short of what is needed to conduct a vigorous research effort that will lead to new treatments and eventually a cure. And it will be far short of what is necessary to give hope to people like me who don't have decades to wait for a cure.

STEM CELL RESEARCH

Recent findings of the isolation of embryonic stem cells, capable of forming all cells of the human body, holds tremendous promise for saving human lives. These cells have the potential to become a source of replacement cells for any failing organ enabling therapies to treat conditions that otherwise would be addressed by whole organ transplants. They also have the potential to fundamentally change pharmaceutical development by allowing researchers to study the beneficial and toxic effects of drugs on many different cell types and potentially reduce the numbers of animal studies and human clinical trials required for drug development.

It is not unrealistic to imagine that, with appropriate funding of research, that scientists may soon learn to produce healthy, dopamine-producing neurons for the treatment of Parkinson's disease. Indeed, in recent hearings of the Senate Appropriations counterpart to this Subcommittee, the stem cell experts called to testify on its promise identified Parkinson's as the first disorder for which a stem cell therapy is likely. This means, in short, that my rescue from Parkinson's may be speeded by this research, and that those breakthroughs will assist the development of comparable therapies for other, equally terrible disorders.

The Parkinson's Action Network understands that there is some concern about the research in embryonic stem cells and the source of those cells. We also understand that it may be some years before stem cell technology produces benefits for patients, many years of further research may be necessary to overcome technical hurdles and that the effort will require a significant funding investment. It is exactly for that reason that we cannot afford any unnecessary delay.

Just as Congress grappled with and supported research on fetal tissue transplantation because of its enormous life-saving potential, so too should it support stem cell research. Without government support, there is little accountability and relatively little accessibility to the larger scientific community. And just as Congress adopted thoughtful, workable, ethical guidelines and protections in support of fetal tissue transplantation research based on the findings and recommendations of the NIH Fetal Tissue Transplantation Panel, so too the government can develop clear ethical guidelines and protections in the arena of stem cell research.

Stem cell research is too promising to impede or stop altogether. We urge the Committee to support this potentially life-saving research.

Thank you.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS

I appreciate the opportunity to provide the subcommittee members the position of the 5,600 National Association of Pediatric Nurse Associates and Practitioners (NAPNAP) members. I respectfully request that our statement be included in the record.

Founded in 1973, NAPNAP is the largest nursing organization dedicated solely to improving the quality of health care of children from birth to the age of 21. Pediatric nurse practitioners (PNPs), are registered nurses with advanced education and training who provide health care services and have prescriptive authority in 50 states. Nurse practitioners (NPs) were recognized in the Balanced Budget Act of

1997 as primary care providers and are directly reimbursed by the Medicare program in all settings. Now more than ever, advanced practice nurses like PNPs are front line, point of contact providers of primary care services to an increasing number of Americans—often delivering services to our most vulnerable populations.

PNPs deliver a broad range of services to children from birth to age 21. They regularly perform physical examinations, treat common childhood illnesses, coordinate the care for children with chronic illnesses, and help families with other critical health care needs. NAPNAP is extremely concerned about the Federal government's involvement in nursing licensure—an area traditionally left to the purview of the states—and respectfully requests that the subcommittee not fund any activities related to a multistate Nurse Licensure Compact initiative. Additionally, NAPNAP urges the subcommittee to recognize the integral role played by PNPs in private sector and government initiatives to improve access to primary care services, especially in rural and medically underserved areas. We request your favorable consideration of the following spending levels for these three programs:

(1) Nurse Education Act: 10 percent increase over fiscal year 1999 funding to $74.6 million and fully fund NP education programs.

(2) National Institute of Nursing Research (NINR): 15 percent increase over fiscal year 1999 funding, commiserate with funding increases to other institutes.

(3) National Health Services Corps (NHSC): continue to support the NHSC at current levels for nurse practitioner programs and urge the appropriate utilization of PNPs.

FEDERAL INVOLVEMENT IN NURSE LICENSURE COMPACT ACTIVITIES

Of critical importance to NAPNAP is the subcommittee's continued vigilance in keeping the federal government out of the business of funding a misguided proposal to alter the regulation of nurse licensure. Last year, the Congress recognized the lack of support around a proposal for states to enter into the proposed Nurse Licensure Compact. The compact radically alters nursing regulation and requires states to abdicate their authority to set licensure standards. In the conference report for the Omnibus Consolidated and Emergency Supplemental Appropriations Act, 1999, Congress deferred taking action on a recommendation contained in the Senate report regarding the interstate nurse licensure compact, pending the resolution of important issues. Since the model multistate licensure compact legislation was released in 1997, only Utah and Arkansas have entered into this agreement. Conversely, a growing number of nursing groups, State Attorneys General, and administrative law experts have raised grave concerns about the constitutionality of the agreement and its long term impact on nursing, other health professions, and access to health care services.

The fiscal year 1999 appropriations conferees "understood that several States have not endorsed the compact and some State Boards of Nursing and other Nursing Organizations have raised reservations about the compact." Since that report, none of the overarching concerns about the compact have been resolved and there are no plans by the organization pursuing this legislation to make changes to the legislation. Given that, NAPNAP urges the subcommittee to reject any proposal to fund the costs associated with the adoption of the nurse licensure compact.

NURSE EDUCATION

The Health Professions Education Act is the sole source of federal support for advanced practice nursing education. Advanced practice nurses (APNs) include nurse practitioners, certified nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists. APNs are in increasing demand in the health care market, and traditionally have filled the void in communities that have not been able to attract a primary care physician. In many rural and medically under-served areas, NPs have contributed to a decline in emergency room visits, and by extension a decrease in health care expenditures by patients and insurers. Continued support for a diverse group of advanced practice nurses prepared as primary care providers will enable the government to honor its commitment to meeting the primary care needs for all Americans.

Last year, Congress passed the Health Professions Education Act of 1998 (PL 105–392), which reauthorized the Nurse Education programs, consolidated some funding programs, and directed the Division of Nursing to conduct a workforce study to better understand the role and need for nonphysician practitioners such as NPs. NAPNAP respectfully requests that funding for the APN category of the Nurse Education Act receive a 10 percent increase over fiscal year 1999 levels. We urge the subcommittee to fund the NP/midwifery program within the APN category—at a minimum—to the fiscal year 1999 levels.

Part of the Health Professions Education Act which passed last year included a "hold harmless" provision for the NP/midwife education program until the workforce study was produced. The Division of Nursing has not completed this study, and we believe that the intent of the authorization was to keep the NP/midwife program at least funded at the level of fiscal year 1999. We request that the subcommittee maintain the "hold harmless" intent of the law.

NATIONAL INSTITUTE FOR NURSING RESEARCH

The National Institute for Nursing Research (NINR) is one of the smallest NIH entities despite the growing responsibility of nurses, especially advanced practice nurses, for the primary care and case management of patients in all settings. In fiscal year 1999, NINR received a budget increase of only 10 percent over fiscal year 1998, less than the 14.7 percent budget increase for the overall National Institutes for Health. To compensate for the disproportionate increase last year and in line with anticipated fiscal year 1999 NIH spending, we respectfully request that the subcommittee endorse an increase for NINR commensurate with overall NIH funding levels.

This increase would provide funding sufficient to empower NINR researchers to explore the vast complexities of "end-of-life" care; a research area for which NINR was identified as the lead institute. End-of-life care involves the synthesis of complex care, pain management, and mental health services for patients and their families. Furthermore, NINR represents researchers who come from the largest health care profession—nursing. Nurses have been at the forefront of many breakthrough developments in patient care, outcomes, and cost effectiveness; avoiding low birth weight babies; and maximizing the quality of life of people living with chronic conditions. As the subcommittee knows, nurses continue to be front line providers of care for the growing population of our nation's elderly. Research which will directly benefit services deserves sufficient NIH financing.

NATIONAL HEALTH SERVICE CORPS

The National Health Service Corps (NHSC) has been instrumental in delivering vital health care services to rural and medically underserved areas. In December 1997, the Federal government estimated that close to 30 million individuals lived in underserved areas and 5,385 primary care providers were necessary to meet existing demand for health care (Senate Report 105–220, p 14). In addition, there are 146 counties without a physician, more than 50 percent of which are being served by a NP or a physician assistant (PA). NHSC funding makes this possible; however there are still approximately seventy counties not served by either a physician, NP, or PA and could benefit from NHSC support. We urge your continued support of this important program.

Furthermore, NAPNAP has grave concerns regarding a shift in the National Health Service Corps policy on the placement of PNPs in underserved areas. Traditionally, the program has paid for both family nurse practitioners and pediatric nurse practitioners; however in 1997, NHSC moved to eliminate PNPs from consideration for NHSC scholarships without any assessment mechanism as to whether this detracts from the government's ability to meet community needs. This shortsighted policy fails to recognize diverse community needs and the PNP's overall nurse practitioner preparation. Because of the impact of this policy on patient access to care, we urge the committee to support report language directing NHSC to reinstate PNPs as eligible scholarship recipients for these rural and medically underserved sites.

On behalf of NAPNAP, I thank the committee for this opportunity to present our views on the vital funding of nursing programs. We look forward to working with you through the appropriations process and welcome any questions, comments, or concerns you might have.

PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

The National Alliance for Eye and Vision Research (NAEVR) is pleased to have the opportunity to submit its views on fiscal year 2000 funding priorities. NAEVR is an umbrella organization of twenty-eight professional, lay advocacy and industry organizations dedicated to eye and vision research.

We would like to begin by thanking you for your commitment to medical research supported by the National Institutes of Health (NIH) and the National Eye Institute (NEI). Mr. Specter, you and your colleagues have been tremendously supportive of pushing the frontiers through support of the NIH. Without this support we would

not be on the verge of many new discoveries in eye and vision research. We are beginning to reap the benefits of our investment due to the amazing advances in basic and clinical science, but more and more we are forced to prioritize what areas of research to support because we do not have the funding available to fund all of the opportunities that exist. This is true in all areas of vision research, and in the public and private sectors.

FISCAL YEAR 2000 FUNDING REQUEST

The sixth strategic plan of the National Advisory Eye Council, entitled Vision Research—A National Plan: 1999–2003, provides for a professional budget recommendation of $456.1 million, 15 percent over the fiscal year 1999 level. This recommendation is in line with the Ad Hoc Group for Medical Research Funding's recommendation of a 15 percent increase, which our 28 member organizations wholeheartedly support. Key research priorities which are well identified in the strategic plan include the following:

—Retinal Diseases: Identify novel causes of inherited retinal degenerations; further examine the cellular and molecular mechanisms whereby identified gene defects cause retinal degenerations; begin to determine the cellular sites of retinal gene expression in development and in health and disease

—Aging: Determine if there are novel markers that differentiate the normal aging process from the diseased process; identify genes and genetic loci contributing to glaucoma, especially those responsible for the most common form of the disease, and characterize the function and interaction of their gene products

—Growth Factors: Determine the role of peptide growth factors, such as neurotrophins, in the development, plasticity, and regeneration of the visual pathways; determine how critical periods are regulated and manipulate the molecular signals underlying this regulation to enhance the adaptive and regenerative properties of the adult brain

—Clinical Research: Improve our understanding of the nature and course of glaucoma, incorporating studies of comorbidity, natural history, and genetics with special emphasis on Hispanic, Native American, and African-American populations; develop improved diagnostic techniques encompassing measures of visual function, optic nerve, and nerve fiber layer structure, in situ and for clinical applications of genetics; investigate the effectiveness of immunomodulating therapies in halting disease progression in optic neuritis; identify the unique characteristics of ocular muscles that render them vulnerable to Graves' ophthalmology, myasthenia gravis, orbital myositis, and chronic progressive external opthalmoplegia.

DISPARITY IN NEI GROWTH VS. NIH GROWTH

Mr. Chairman, the eye and vision research community is becoming increasingly concerned about the disparity in growth between the NEI and the NIH. We have analyzed specific trends with regard to the Administration's Requests and the Congressional Appropriation for NEI funding and are alarmed at several patterns which have emerged. Most importantly, when these trends are analyzed and, appropriations are adjusted for inflation to reflect real purchasing power, the NIH has grown by more than 60 percent while the NEI has grown by only 24 percent since 1985.

How has this level of disparate growth occurred? There have been many factors contributing to this disparate growth rate. As an example, in fiscal year 1999 the overall increase in the budget request for NIH was 8.4 percent while the NEI request was 8 percent. What alarms the eye and vision research community is the fact that when the Appropriations Process was completed the overall NIH increase was 14.7 percent while the percentage increase for the NEI was 11.3 percent, the second smallest of all NIH Institutes. Mr. Chairman, we have been informed that the Committee's distribution of resources above the Administration's proposal was done in collaboration with the scientific experts at the NIH in order to support the laudable objective of scientific priorities, not politics, driving the allocation of resources. Regrettably, the tremendous research opportunities in eye and vision research do not fare well under this scenario. At some point in these closed deliberations the opportunities and pressing health needs in eye and vision research are overlooked or deemed to be of lower priority when compared to other research opportunities. We would submit to both the Congress and the Administration that eye and vision research is a pressing priority in the context of improving the health and welfare of the fastest growing segment of the American populationthose over 65 years of age. We would also submit to the Congress that this trend in resource allocation must be given more careful scrutiny.

We have been informed by some sources at the NIH that one of the critical variables influencing the allocation of resources among the Institutes is the issue of success rates for research grants. The NEI has one of the highest success rates among the NIH Institutes. The Institute does not support a broad network of specialized research centers or other "umbrella" grants as many of the other Institutes do. Therefore, the resources provided to the NEI are made available to the extramural research community primarily through the research grant mechanism to individual investigators. As a result, NEI's success rate is frequently better than the other categorical Institutes, disadvantaging the NEI from receiving additional resources to "bring up the success rate" of investigators. Thus, the NEI is disadvantaged in terms of growth and pursuit of scientific opportunity.

GROWING THREAT OF BLINDING EYE DISEASES

When asked what sense do you fear losing the most a majority of Americans respond "vision". In the U.S. today more than 1.1 million Americans are legally blind and an estimated 80 million are at risk of developing potentially blinding eye diseases. 120 million Americans wear corrective glasses or contact lenses and 12 million suffer from some form of visual impairment that cannot be corrected by glasses. Diabetic retinopathy is the leading cause of blindness for Americans under 60, accounting for 12 percent of new cases of blindness each year (24,000 people). Persons with diabetes are 25 times more at risk for blindness than is the general population. The annual cost of eye and vision disorders is $38.4 billion.

As our population ages, these costs will increase significantly and present many challenges to our health care system. In fact, by the year 2030, the elderly population in the U.S. is expected to double and more than 66 million Americans will be at risk for common eye diseases. It is only through further advances in research that we are going to gain a better understanding of vision disorders that can lead to cost-effective advances in disease prevention and treatment. We now have the scientific and technological capability to make substantial progress in all areas of eye and vision research, if an expanded research effort is supported. This research progress will only be possible if we can insure that the NEI has the resources necessary to pursue initiatives in the key areas outlined in the Vision Research Plan. In order to give you a sense of the research needs and opportunities that exist today, we will outline several diseases and disorders where research has the most promise.

AGE-RELATED MACULAR DEGENERATION

The leading cause of blindness in the elderly is age-related macular degeneration (AMD), a retinal disease which causes loss of central vision. More than 1.7 million Americans over age 65 suffer from AMD and this number is expected to triple by the year 2020. At the present time, there is no cure for AMD and treatment remains limited. While laser treatment has been found to have some effect in delaying some forms of AMD, no current treatments exist that will reverse the slow loss of central vision that results from this disease. However, recent research developments are encouraging. Scientists have mapped genes of several different forms of inherited macular disease, are exploring retinal transplantation and growth factors, and are testing new treatments including the effects of antioxidant on the progression of AMD. The NEI is also actively pursuing studies in the use of alternative therapies for the treatment of AMD. The Age-Related Eye Disease Study (AREDS), which is designed to improve our understanding of AMD and cataract, includes the study of the effect of vitamins and antioxidants as treatments for AMD and cataract.

LOW VISION

A related area of concern is low vision, or vision impairment which is not correctable by glasses or contact lenses. As many as 12 million Americans suffer from visual impairments which affect their ability to read, drive, work, and perform many everyday activities we all take for granted. The most common eye diseases which cause visual impairment in adults are AMD, cataract, glaucoma, diabetic retinopathy, and optic nerve atrophy. Even more serious are the eye diseases which cause visual impairment in children. These include retinopathy of prematurity, cortical visual impairment, and coloboma. Low vision in children often affects their development and results in the need for special education, vocational training, and social services throughout their lives. The cost of these impairments is more than $22 billion each year.

Under the auspices of the National Eye Health Education Program (NEHEP), NEI is working with its private sector partners to launch a program directed at low vision in order to increase public awareness about visual impairment and the impact

it has on everyday life. The program will provide information about low vision services and the devices which are currently available to assist those with visual impairments. This effort will not only be directed at those suffering from visual impairments but also to medical professionals, eye care specialists, managed care organizations, and family members. NAEVR supports this public education partnership and encourages the Committee to support it as well.

DIABETES

Diabetic retinopathy, the leading cause of blindness in individuals with diabetes, causes vision loss in more than 24,000 Americans each year. In fact, if a person has diabetes, they are 25 times more likely than the general population to go blind. Despite the success of research in developing treatments to slow the progression of blindness, little is known about the mechanism that triggers diabetic retinopathy.

Researchers supported by the NEI are focusing their research efforts on gaining a better understanding of diabetic retinopathy by examining the cell biology of the retina, including cell growth factors; how blood flow is regulated in the retina; and the development of new drugs which inhibit an enzyme which appears to be involved in the development of diabetic retinopathy. Research in these areas will lead to better treatments, strategies for prevention, and hopefully, a cure.

GLAUCOMA

As many as three million Americans have glaucoma and approximately 120,000 are blind because of this disease. It is the leading cause of blindness in African Americans and the second leading cause of irreversible vision loss overall in the United States. Glaucoma is a predominantly age-related disease and is especially prominent in the elderly population (75–80+). Specifically, at least 5 percent of white Americans and 10 percent of black Americans in this age group have this disease. In the last five years, as a result of NEI-sponsored glaucoma research, three new drug therapies, which lower intraocular pressure, have been introduced. Unfortunately, however, many individuals with glaucoma are not receiving treatment because glaucoma usually has no symptoms in its early stages and they are unaware that they have the condition.

CATARACT

Cataract is the leading cause of blindness in the world. A cataract is a lens opacity which interferes with vision. It occurs most often in adults 50–60 years and older. In the U.S., 1.35 million cataract surgeries are performed each year to remove cataracts at an estimated cost of $3.5 billion, much of which is paid for by Medicare. Because the U.S. population is aging, it will be important to focus our research on what aging factors lead to cataract. At this point, little is known about events which trigger cataract formation. Several major hypotheses have been proposed to explain age-related cataracts. Researchers must now turn their attention to proving or disproving these hypotheses and improving our understanding of cataract formation.

CONCLUSION

Mr. Chairman, the members of NAEVR are supportive of an increased research focus on eye and vision disorders, such as those outlined above, and hope that the Committee will allocate additional funding to the NEI to allow these critically important research efforts to continue and expand. As we enter the 21st Century, we must ensure that we are doing our best to find ways to prevent and treat eye and vision disorders, and are providing quality eye care services and devices for those who are already suffering from visual impairment.

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

We are requesting your support for increased funding for the National Institute on Drug Abuse (NIDA) in the fiscal year 2000 Labor, Health and Human Services appropriations bill. The College on Problems of Drug Dependence (CPDD) is the nation's longest standing organization addressing drug dependence and drug abuse.

It is estimated that drug abuse and addiction cost the American public more than $110 billion per year, and the most effective means for reducing these costs is through improvement of drug use prevention and treatment. NIDA's scientific advances in understanding, treating and preventing drug addiction are making a dramatic impact on drug addiction treatment throughout this nation. Drug abuse treatment can be both effective and cost-effective resulting in dramatic drops in drug use and criminal behavior rates as well as improvements in physical health, social func-

tioning, and employability. We believe that it is imperative to continue to invest in drug abuse research and the development of new effective and cost-effective treatments.

The College recognizes the complexity of preventing and treating drug addiction. It is a health problem that defies simple solutions. Drug addiction is not a singular disease state that afflicts everyone similarly but rather an amalgamation of societal influences, genetic predisposition and comorbidity that when combined with the insidious properties inherent in drugs of abuse produces a clinical picture often easily recognized but difficult to prevent and treat. While the youth of our nation represent our most vulnerable population, the adults imprisoned for drug-related crimes represent one of our greatest financial burdens. The regression in both ranks in the future requires the development of more effective drug prevention programs. Yet, treating these disparate groups, as well as many others, requires tailored treatment programs that comprise behavioral modification as well as treatment with current and new medications. The College applauds the successes of NIDA in bringing new prevention strategies to unique populations and alerting the nation to new dangers through their epidemiological surveillance. Many of the College's members are treatment specialists who are poised to transfer their new forms of successful addiction treatments to the medical community through NIDA's new Clinical Trials Network. Yet, the heart and soul of the College and NIDA lies in the search for the biological basis of drug addiction. We are united in the goal of understanding the fundamental biological responses that sometimes bonds an individual to a never ending quest for self-administration of drugs. We recognize that unraveling the genetic code will provide the future answer as to why one individual succumbs to drug addiction and another is immune.

Indeed, drug abuse research is coming of age. NIDA was established just over two decades ago. It funds virtually all drug abuse research in the United States and more than 85 percent of all drug abuse research worldwide, few other governments support this research. There is little pharmaceutical industry research in this area and few foundations support any basic research, since the market potential for medications in this area is fairly modest. Despite NIDA's successes in developing new strategies for prevention and treatment of drug dependence, we are still faced with enormous challenges. New drug threats emerge, such as the recent methamphetamine epidemic, and shifting socioeconomic factors are just two of many factors that represent new struggles. However, the comprehensive portfolio of NIDA research agenda bodes well for the future.

The research dissemination and training programs of the Substance Abuse and Mental Health Services Administration (SAMHSA) are also an essential part of our national drug abuse treatment and prevention strategy. We are especially supportive of the training and demonstration grant functions of the Center for Substance Abuse Treatment (CSAT) and the Center for Substance Abuse Prevention (CSAP). We need more research on the barriers to the implementation of effective new treatment and prevention programs. The treatments and the prevention strategies that emerge from NIDA-supported research require community-based programs to evaluate their effectiveness. CSAT and CSAP demonstration grants provide a critical link between research and its implementation. We do not have a specific recommendation for SAMSHA but we request that adequate support be provided for the demonstration and training programs supported by CSAT and CSAP.

Thank you for the tremendous support and leadership you have provided during the last three fiscal years. We sincerely appreciate the 14.7 percent increase provided to NIDA in this fiscal year 1999 and urge that you increase this base in fiscal year 1999 to continue the ongoing peer-reviewed research funded by NIDA. Such research is essential for continuing to further our understanding of the etiology, prevention, and effective treatment of substance abuse problems. In fiscal year '99 NIDA was funded at $608 million. We ask for your support in increasing funding for NIDA by at least $94 million (15 percent) in the fiscal year 2000 Labor, Health and Human Services Appropriations bill. This increase is consistent with efforts to double the entire NIH budget over a five-year period. We arerequesting an additional $30 million for funding the Clinical Trials Network. These additional funds will enable NIDA to fund ten new nodes in the Network that is vital for transferring new treatment knowledge to the medical community. Funds for the Clinical Trials Network are essential so as to avoid jeopardizing other vital programs at NIDA.

Thank you for your time, and the opportunity to present the views of the College on Problems of Drug Dependence.

PREPARED STATEMENT OF DANIEL D. VON HOFF, M.D., PRESIDENT, AMERICAN ASSOCIATION FOR CANCER RESEARCH

Good morning, Mr. Chairman and Members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies. My name is Dan Von Hoff. I am a doctor who has had the privilege of taking care of people with cancer over the last 20 years. I am also privileged to be President of the American Association for Cancer Research, the largest group of physicians and scientists dedicated to the cure and prevention of cancer in the world. And lastly, I am a cancer survivor.

I know that for you and other Members of Congress there are many priorities and many requests. However, it is time to make cancer our highest health care priority and undertake a national approach to eradicate cancer.

Cancer deaths fell for the first time in decades. This is a fall in the death rate. The percentage of the patients who will die from their cancers has gone down. This is a remarkable achievement and means that our treatments are beginning to have an effect. It also means that some of our prevention strategies are working. The death rate is going down! Still, remember that, even though the death rate from cancer is going down, cancer still kills more Americans each year than have died in all the wars we have fought in this century.

However, because our population is aging and, thank goodness, we are all living longer, the number of people who will develop cancer in the United States will increase dramatically. If current rates are used to calculate the figures, the number of estimated new cases is expected to increase by 29 percent by 2010. Looking beyond 2010, the number of cancer cases is expected to reach 2 million new cases per year by 2025.

Cancer will reach epidemic proportions. Remember that 1 of every 2 men and 1 of every 3 women will get cancer in their lifetime. This epidemic will be a tremendous burden on the patients, their families, most certainly on this country and its health care system. Conservatively estimated, the projected economic burden due to the direct cost of treatment will increase to approximately $65 billion per year and the "productivity" cost (lost economic productivity due to disability and death) will grow to over $135 billion, for a total expected economic burden of over $200 billion annually in 10 years.

What can we do to help head off this epidemic? There is hope if we take more actions now.

Why is there hope? The death rate for patients with cancer has decreased because of:

(1) Earlier Detection.

(2) More effective and less toxic treatments for patients with advanced cancer.

(3) Prevention.

I will address each of these in turn:

Earlier detection advances including mammograms for early detection of breast cancer, examinations of stool for blood to detect colon cancer, and tests for PSA's to detect prostate cancer have helped us to find these cancers earlier, when they are more curable.

We are having much greater success in treating advanced cancer in patients. In a CAT scan of a patient's liver, it is possible to see breast cancer (large, obvious holes) before treatment, and clear of these holes after treatment with a new anticancer agent. She had a remarkable shrinkage of the tumor and is alive and well and working 8 years later with no evidence of disease. So, even advanced disease can be eradicated in some patients.

And we are learning how to prevent cancer:

(1) First of all, stop smoking, stop smoking, stop smoking. Tobacco is responsible for more than 30 percent of all cancer deaths.

(2) The New York Times documented the first major advance in prevention about one year ago when they reported that the antihormonal agent Tamoxifen could reduce the incidence of breast cancer in women who are at high risk for the disease.

The effect of Tamoxifen was dramatic in the first 3 years. Tamoxifen reduced the risk of invasive breast cancer by 49 percent, and early (non-invasive) breast cancer by 50 percent. There were some side effects on which we are all working to improve, but the reduction in risk is truly an important result.

In addition, I have just come down from Philadelphia, where the American Association for Cancer research held its largest international meeting. More than 10,000 researchers, physicians, survivors, advocates, and citizens learned about the breakthroughs in basic cancer research, which are the result of exciting advances in molecular biology and genetics; the discovery of new agents for treatment; and the latest strategies in cancer prevention. These include, among others:

(1) Dramatic evidence that lycopene, a naturally occurring substance in tomato products already linked to cancer prevention, may even be effective in treating prostate cancer.

(2) A new therapy for lung cancer is being developed that combines the promising approaches of gene therapy and anti-angiogenesis therapy, or cutting off the formation of blood vessels near cancerous tissues.

(3) Additional good work on discovering how NSAIDs, common compounds such as aspirin, may work together with other agents as powerful new anti-cancer agents.

How can we continue to decrease the death rate from cancer? How can we make sure the increasing number of patients who will get cancer will survive it? I work at the laboratory bench, as well as in the clinic, seeing patients on a daily basis, trying to get new therapies to patients as quickly as possible. I believe there are six key areas of investment that will enable us to rapidly and efficiently translate our laboratory bench research findings into effective cancer treatment and prevention. We need to get ideas from the bench to the bedside. We can do that with these investments and make a real difference. They include the initiatives listed below:

(1) Increase the level of funding for investigator-initiated research. Our best ideas to cure or prevent cancer came from individual scientists working in the laboratory and with patients. Currently, less than a third of peer reviewed and approved research grant requests are funded. There are so many good research projects, which cannot be done because of a serious lack of funding. The NCI budget should be increased to enable funding of 45 percent of scientifically meritorious grant proposals.

(2) Increase the number of NCI-designated Comprehensive Cancer Centers in the United States. This would improve the geographic distribution of expertise in cancer research and patient care and maximize patient access to the most up-to-date cancer treatment and prevention strategies.

(3) Expand our clinical trial programs. Currently, only 2 percent of adult patients with cancer participate in clinical trials. It has been shown that patients participating in clinical trials have better survival rates than those who do not. And this is how we make our advances in human cancer. Having more patients on clinical trials means more patients will receive the most advanced treatment and prevention approaches to their particular cancers.

(4) Attract, educate, and train more cancer researchers. We need continued replenishment of leaders to bring findings from the laboratory bench to the bedside. The terrible uncertainties about stable funding of cancer research efforts decrease our abilities to recruit and keep young investigators in the field of cancer research. They will be the ones caring for us and trying to prevent cancer in us in the future.

(5) Double funding for cancer prevention, and establish "centers of excellence" to support a proactive national initiative in cancer prevention.

(6) Enhance strategies and infrastructure to support public-private partnerships on cancer therapeutics.

What is the investment for making sure we take advantage of these opportunities to head off an epidemic of deaths from cancer? We strongly recommend the implementation of a 5-year plan to achieve an annual investment level of $10 Billion per year for cancer research. Currently, our investment is $2.7 Billion per year. We propose that we begin doubling the current NCI budget in fiscal year 2000 and increase the budget by 20 percent per year for the next four years until we reach the $10 Billion level! Can this money help? You bet it can, because now we have the tools, the genetics, the understanding to make a difference in developing new treatment and prevention strategies. Further, an annual investment at the level of $10 Billion is an appropriate investment, considering the enormity of the cancer burden that we face in the future. We estimate that such an investment would reduce cancer deaths from 25–40 percent over a 20-year period, saving 150,000 to 200,000 lives each year in the United States.

The AACR fully endorses the Report from The March Research Task Force, which describes these recommendations in detail. This cogent report was circulated to all Members of Congress within the past few weeks and we recommend its immediate implementation.

In closing, I would like to take this opportunity to mention one final item. Today is April 15th—tax day, a day when all of us in this country show our good faith to contribute to the greater good. There doesn't appear to be too many people who want to pay more taxes. There is however, an exception. In a survey reported in USA Today by Cindy Hall and Terry Mceemak, 87 percent of adults in the United States said that they would willingly pay more taxes for cancer research.

Our citizens feel the burdens of cancer each year, they know it is increasing, and they want it to end. Unless we act with urgency now, at the current rate, the

human and economic cost of cancer in the United States will become totally unmanageable within the next decade.

Thank you for your attention. I would be glad to answer any questions you might have as you deliberate this important matter.

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the 30,000 children and young adults with cystic fibrosis (CF), the Cystic Fibrosis Foundation is pleased to submit public witness testimony to support fiscal year 2000 appropriations for the National Institutes of Health (NIH). Cystic fibrosis is a fatal, genetic disorder that occurs in one out of every 3,900 births in the United States. Only a few decades ago, parents of children with CF could expect their sons and daughters to survive less than five years, and the struggle to survive even that long, involved tragic suffering. Research has led to a variety of treatment options for children born with CF, including antibiotics, nutritional support and a novel biotech drug to thin dangerously thick lung secretions.

Medical researchers have made incredible advances in the treatment of individuals born with CF. As a result, children are now living into adulthood and the opportunities to cure this disease grow stronger every day. Several clinical trials are underway to evaluate the effectiveness of drug strategies that seek to correct the basic CF cellular defect, rather than treating symptoms alone. Correcting the cells, whether with gene therapy or with drugs that repair the protein product of the gene, should prevent the destructive cascade of damage this disease causes to multiple organ systems. In large measure, this progress can be attributed to the commitment of the members of this Subcommittee, and to your colleagues who preceded you. On behalf of the entire cystic fibrosis community, please accept our heartfelt gratitude and thanks for believing in the potential of our medical research enterprise. You have helped to bring the hopes and dreams of a cure for CF closer to a reality for these young men and women.

The partnership between the NIH and the CF Foundation provides a base for leadership in this country that is unparalleled. This leadership plays a critical role in guiding the programs that will one day produce a cure for this deadly disease. Together, we have built an extensive pipeline of new scientific discoveries that will be translated into lifesaving treatments for thousands of individuals with CF. Much of this CF research has been made possible because of this Committee's continued support and vision to nurture and expand our nation's biomedical research.

For fiscal year 2000, the CF Foundation urges continued commitment to double the budget of the NIH over five years. The first step this Committee took toward this objective in fiscal year 1999 was greatly appreciated by the research community as well as by patient advocates. The CF Foundation believes that the resources you have put in place to carry out CF medical research are a laudable and imperative national priority. In urging your consideration of this important request, we are joined by the entire medical research community represented by the Ad Hoc Group for Medical Research Funding. We call on the U.S. Congress to commit to a significant and sustained growth in funding and reach a doubling of the budget in the next five years.

CF is a disease that requires a vigorous investment by all of the partners in our research enterprise. In addition to the NIH research, individuals with rare diseases like CF, need biotechnology companies to be an important partner in the effort to develop new therapies. However, the current economic climate in the biotechnology industry has made it increasingly difficult for the majority of biotech companies to invest in rare diseases. The cost of developing products for which there is a limited market (small patient numbers) often creates a barrier. Progress in CF research is threatened if we fail to create the appropriate incentives and opportunities to overcome this barrier.

The Orphan Drug Act has been helpful in providing some financial incentives, but innovative approaches must be made by private foundations and the NIH to further encourage the development of novel therapies by our biotechnology industry. In 1998, the CF Foundation launched the Therapeutics Development Program (TDP)—the most extensive research initiative in its history. This program bridges the gap between the discoveries in the laboratory and vital new CF medications. Specifically, the initiative provides funds for two mechanisms. First, it supports a model clinical research center network of seven highly trained centers where drugs will be tested. And second, it offers matching funds to support research at selected biotechnology companies. This program is solely funded by the CF Foundation to fill a void that the current structure of public resources and industry investment had created.

Researchers and clinicians at the Therapeutics Development Center network evaluate drugs through the latest techniques and comprehensive study design. The network was created to capitalize on the increasing number of discoveries being made about the basic defect in CF. By establishing specialized clinical centers, researchers can seize these opportunities to intervene in the disease process through new CF treatments. The clinical research will also build upon early phase trials already underway in CF gene therapy and protein-assist therapy, as well as studies to test anti-infective drugs.

The Therapeutics Development Center Network now has four different drugs being evaluated, and in the "pipeline." At each of the seven centers, state-of-the-art clinical research is being conducted at the fastest possible pace. The staff, recently trained by the coordinating center (at Children's Hospital and Regional Medical Center in Seattle) in the latest clinical research techniques, will carry out the first two of three phases of clinical investigation. Specifically, the seven Therapeutics Development Centers will focus on expediting the early phases of clinical trials that evaluate safety and dosing regimens for new drugs. The final phase, which assesses the drug's effectiveness in a large population of patients, will involve the CF Foundation's full network of 113 accredited care centers across the country.

Mr. Chairman, the CF Foundation has created a unique program to address a critical gap in our research infrastructure. However, additional gaps exist. We encourage the NIH to also seek innovative ways to attract the biotechnology industry to conduct research that could have an impact on orphan diseases. The translation of new knowledge from the laboratory to CF patients requires that the NIH consider novel approaches to private-public collaboration for orphan diseases.

We request your continued support for the full spectrum of research—basic, translational, and clinical—all sponsored by the National Center for Research Resources, the National Institute on Diabetes, Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung and Blood Institute (NHLBI). The resource capacity of these institutes is of paramount importance to push the frontiers of CF research ahead. As you deliberate the allocations of resources for fiscal year 2000, we hope that you see the following as clear priorities to support.

National Center for Research Resources (NCRR): We would like to highlight the outstanding support that the NCRR has provided to the field of CF research in the past, and most especially fiscal year 1999. The NCRR plays a pivotal, and often overlooked, role in the research community's ability to achieve its objectives. We would submit to the Committee that many research investigations are slowed or hampered by a lack of research resources. The NCRR has worked diligently to establish a pilot data monitoring center at a general clinical research center which is jointly funded by the CF Foundation through the Therapeutics Development Network Program. This data monitoring center expedites the collection, manipulation, and evaluation of data gathered across multi-center trials on CF therapies. This initiative represents a tremendous collaboration and the Foundation is honored to work with the NCRR in providing support to this important endeavor. CF patients are heavily dependent upon the vast resources in academic institutions that the NCCR supports; we urge that the Committee strengthen the resource commitment to this important component of the NIH enterprise.

One critical issue hampering evaluation of new and novel therapies for CF that we bring to the Committee's attention is the cost structure in the General Clinical Research Centers (GCRCs). The current cost structure of the GCRC's has two rates, one for NIH-sponsored research and a separate, and higher one, for industry-sponsored research. This system uniquely disadvantages small biotechnology companies from working on orphan diseases since they are unable to pay the same per patient rate in clinical investigations as well-established companies. We at the CF Foundation believe that the NIH and the NCRR should recognize the unique constraints of the biotechnology industry and create a more favorable environment for industry-sponsored clinical research through the GCRC mechanism. Adjusting the current cost structure for biotechnology companies to conduct clinical trials for orphan diseases through the GCRC program will greatly advantage drug development for diseases such as CF.

National Institute of Diabetes, Digestive and Kidney Diseases: We ask that this Committee direct the NIDDK to develop key mechanisms to assure rapid translation of basic research into new therapeutic interventions. While we applaud the acquisition of new knowledge through current programs at the NIH, we must nurture clinical research and clinical investigators. In fiscal year 1999, the CF gene therapy centers were re-competed by the NIDDK. The CF Foundation appreciates that many excellent applications for CF gene therapy centers were received by the NIDDK. CF is clearly on the cutting-edge of gene therapy research and the Institute should,

within the incredible increase this Committee provided in fiscal year 1999, strongly support and expand its capacity in this area.

In addition, it is important that the Institute support mechanisms for developing new therapies for CF patients. The Institute's investment in basic research over the years has provided scientists with great insights on how to treat the disease. Now these insights must be fully translated and evaluated through Institute-provided resources.

Also, it is hoped that expanded support of the Small Business Innovative Research (SBIR) Grant Program, especially for orphan diseases like CF, will provide greater opportunities for small businesses to develop new therapies for CF patients. It is our recommendation that the NIH be encouraged to actively pursue and support collaborations with the private sector through the SBIR mechanism for orphan diseases.

National Heart, Lung and Blood Institute: The CF Foundation was pleased to hear of the continued support of SCOR grants and program projects directed toward developing new therapies in CF. Once again, the CF Foundation would like to encourage the NHLBI to explore innovative ways to take the wealth of information that has evolved, as a result of the Institute supporting basic research, and to translate late it into clinical interventions for the disease. The SBIR program initiatives directed toward the development of new clinical approaches to CF would only enhance the opportunity for CF patients to receive lifesaving new therapies.

Clinical Researchers: To effectively exploit our progress in the research laboratory and translate that progress to patients, a cadre of well-trained clinical investigators is of paramount importance. Additional initiatives in post-doctoral training, support for new and young investigators, programs to facilitate mentoring of young investigators and support for the clinical research infrastructure are pressing priorities. Given the current balance of funding, if these priorities are not vigorously addressed soon, we stand to lose the next generation of clinical scientists.

Research Restrictions: The CF Foundation urges Congress to fully evaluate potential riders and subsequent actions to the Appropriations Bill which could be detrimental to the research environment. As an example, last year in the Omnibus Appropriations Bill, an amendment was included which required "federal awarding agencies to ensure that all data produced under an award will be made available to the public through procedures established under the Freedom of Information (FOIA)." This amendment has raised serious concern regarding protected health information as well as the capacity of our medical research infrastructure to respond to these types of inquiry.

Although research results are provided to the funding agency through the structure of the progress report, the breadth of disclosure required by this amendment will have a dramatic impact on the increased cost of conducting research, and potentially slowing the research process. This fiscal year the CF Foundation is aware of the controversy surrounding stem cell research from both the scientific and ethical standpoints. We further understand that this issue is likely to be addressed through an amendment process in the fiscal year 2000 Appropriations Bill instead of in a deliberative Committee process where full disclosure and debate would naturally occur. We urge the Committee to be vigilant in preventing passage of an appropriations bill that would circumvent major policy issues which require thoughtful consideration and deliberation in a public forum.

The CF Foundation realizes the scope of current funding constraints and that federal programs, regardless of their merit, have been placed in competitive positions. Stable, long-term funding will not be possible without a dedicated funding source. Therefore, the CF Foundation is actively working to support legislative initiatives that will augment the resources available to the Committee through its normal allocation.

Thank you for consideration of this request. The CF Foundation looks forward to working with you in the coming months on the vital issue of NIH funding.

Prepared Statement of the National Coalition for Cancer Research

On behalf of the 23 organizations of the NCCR, please accept this testimony to the Committee record. NCCR greatly appreciates the commitment of this Subcommittee and the leadership of Chairman Specter and Senator Harkin to ensure adequate and sustained funding for NCI and NIH. The NCCR is comprised of 23 national research and lay advocacy organizations working to secure adequate federal funding for research to improve cancer prevention, detection, treatment, and survivorship. These 23 member organizations consist of 65,000 cancer researchers, nurses, physicians, and health care workers; tens of thousands of cancer survivors

and their families; 40,000 children with cancer and their families; 90 cancer hospitals and cancer centers across the country; and more than 2 million volunteers.

NCCR is thrilled that NIH and NCI were appropriated the largest increase ever for this fiscal year. In terms of funding for fiscal year 2000, we understand the real funding constraints you are under as imposed by the recently passed Budget Resolution and the current budget caps. Our concern is that NCI and NIH be appropriated sufficient funds in order to support and to sustain the highest quality cancer research, academic research centers, translational research, and clinical trials and to exploit fully the many extraordinary research opportunities available, so that the National Cancer Program can save lives and make real headway in the war against cancer.

Now is the time to focus federal resources on funding and finding a cure for cancer or our country will pay for it later—in dollars and in lives lost. The following statistics put the magnitude of the current cancer pandemic in perspective:

—5 jumbo jets crashing every day for a year equals the 563,100 Americans who will die this year from cancer

—1 out of every 2 American men and 1 out of every 3 American women will develop cancer during his or her lifetime

—1 out of every 4 deaths in the U.S. are caused by cancer

—$107 billion dollars are spent on cancer health care costs annually

There is no more time to wait.

It is important that we are not misled about the problem of cancer in America. While cancer rates—the number of people per thousand in the population who develop cancer in a given year—have dipped slightly by 2.6 percent between 1991 and 1995, cancer incidence, the new cases of cancer reported each year, are expected to increase hugely over the next decades. As the Baby Boom Generation ages, the number of Americans over age 65 will double to 69.4 million in 30 years. Currently, 64 percent of cancer occurs in patients over 65, the Medicare population. By 2010 cancer incidence is expected to increase 29 percent and mortality 25 percent with annual costs exceeding $200 billion. The Medicare program already faces serious problems but will be crippled if cancer prevention and treatment options do not improve significantly over the next thirty years. It is imperative, thus, to mount an aggressive cancer research front immediately.

Americans across the country are demanding that the federal government increase its commitment to cancer research funding. Through the efforts of The March—Coming Together to Conquer Cancer—hundreds of thousands of adult and pediatric cancer patients, parents of children with cancer, oncology nurses, cancer researchers, medical professionals, and cancer research advocates gathered last September on the National Mall and in their state capitols to wage war on cancer and to call for substantial increases in federal funding for cancer research, because current federal funding for cancer research is grossly inadequate.

This year's federal funding for cancer research represents an investment of only $10.75 per person—barely more than the price of one movie ticket and container of popcorn a year! We invest less than 2 percent of the economic toil this disease inflicts. No wonder, then, that only 31 percent of approved cancer research projects receive funding, and cancer is the second leading cause of death for American men and women. I urge this Subcommittee to listen to your constituents, to take heed of the statistics, and to support the bipartisan plan, demonstrated in H. Res. 89 and S. Res. 19, to continue the course to double the budget of NIH in order to advance medical science and accelerate progress against diseases like cancer.

As a nation, we must redouble our commitment to promoting cancer research and eradicating this disease. Increasing the federal commitment to cancer research is an investment that this nation can ill afford not to make. The United States already spends $107 billion annually in direct and indirect costs of cancer, and the costs rise each year. Yet we invest only 2 percent of these costs in research and development to improve prevention, detection, treatment, and survivorship. Most product-oriented industries would fare poorly if they spent only 2 percent on research and development. In fact, the Defense Department spends upwards of 15 percent of its budget on research and development. American businesses invest between 5–10 percent in research and development; some biotechnology and pharmaceutical companies invest more than 15 percent in R&D. These figures are closer to what we should invest in cancer research when juxtaposed against the economic burden of disease. So, what do we do? We support and urge Members of Congress to support The March Research Task Force proposal to increase NCI's budget to $10 billion by doubling the budget for fiscal year 2000 and increasing it 20 percent each of the following four years. This new funding is absolutely necessary to research and to apply new knowledge for improved cancer treatment, detection, and prevention which could enable:

—Accelerating basic and clinical research by funding at least 45 percent of approved cancer research grants
—Accelerating cancer therapy development by creating public/private consortiums
—Accelerating the preclinical and clinical development of cancer therapies
—Improving methods of cancer detection and prevention and their utilization
—Implementing a national research and education initiative in tobacco control
—Developing chemo-preventive agents
—Behavioral research to understand and manage cancer survivorship and end of life issues
—Creating public/private partnerships to engage the private sector in conquering cancer
—Developing a comprehensive, national clinical trials system for cancer drugs
—Researching why cancer occurs disproportionately in minorities and the underserved
—Training a cadre of clinical scientists in oncology
—Improving current research facilities and building new ones
—Creating more research jobs at medical schools, research institutions, specialized cancer treatment centers, and pharmaceutical and biotechnology companies.

So many exciting developments are occurring in cancer research. We are gambling with our lives and our children's lives by not sufficiently or aggressively funding them to exploit the science that we have worked so hard to understand. For example, scientists are just beginning to understand the roles and possible manipulation of the tumor suppressor gene p53. Tumor suppressor genes act like the brakes in cell replication, by inducing programmed cell death. p53 is mutated in 55 percent of tumor types, so that cancer cells replicate out of control. Possible therapies include delivering a virus to target and destroy the mutated p53. Another approach is injecting a virus directly into the tumor site to attack and disarm it by inciting the body's normal immune response. p53 could also indicate which treatment options are the best for individual patients, because certain therapies will be more or less effective depending on whether the patient has mutated or normal p53.

The enzyme telomerase is also an exciting part of cancer research. Excess telomerase is apparent in all major cancers. It rebuilds telomeres, which determine how many times a cell can divide. After each cell division, the tips of telomeras diminish until they are so small that the cell no longer divides. Excess telomerase prohibits this from occurring by constantly re-building telomeres. Research efforts are exploring how to manipulate telomerase levels and control cancer.

In order to accelerate these possibilities for improved cancer treatment, more funding is required. Research opportunities are out-pacing the available funds for research. The President's proposed 2.4 percent increase in NCI funding and 2.1 percent increase in NIH funding would most certainly set back cancer research efforts. NCI estimates indicate that the success rate—the percentage of approved cancer research projects that are funded—would drop from 31 percent to 28 percent. The Director of the National Cancer Institute, Dr. Richard Klausner, noted at the National Cancer Advisory Board meeting in February that it would take three years of budget increases of nearly 10 percent per year to once again reach a success rate of 30 percent. That projection is very conservative. It assumes that NCI will have only a 4 percent increase in grant applications, even though last year NCI was deluged with a 23 percent increase in grant applications. Chairman Porter, our base of science knowledge is growing each day. In turn, this new knowledge is spurring questions regarding applications of new knowledge. It makes sense that funding for research should increase at a level commensurate with new opportunities, then, instead of decrease.

Cancer research makes sense—and dollars, too. 85 percent of the nearly $3 billion appropriated to NCI, will fund extramural research across the country in nearly every state. Every state in the Union benefits in real dollars back home from our investment in cancer research. For example, in fiscal year 1997 researchers in Pennsylvania received $128 million, researchers in Iowa received $9 million, researchers in Missouri received $20 million, researchers in Texas received $102 million, researchers in South Carolina received $5 million, and researchers in Washington state received $83 million. These research dollars also support universities, hospitals, and cancer centers. In 1987, the University of Pennsylvania received over $27 million in NCI support, and Washington University received over $15 million.

Adequately funding the NIH is a sound business investment for the national economy. NIH-sponsored research currently translates into $17.9 billion in employee income, $44.6 billion in sales, and over 726,000 jobs in the pharmaceutical, biotechnology, and medical fields.

In addition to funding, quality research also depends on maintaining the integrity of top-notch academic health centers and research universities. Clearly, these institutions provide the "environment" and many of the resources necessary to a full spectrum of investigational and educational programs. The preservation and enhancement of these centers of excellence is an urgent matter of public concern. The chaotic conditions of the "health care marketplace" and the increasingly severe financial constraints that result, are forcing academic health centers devoted to research and education toward the "endangered species" designation. A strong and vital national research program is one of the cornerstones of preservation for these centers.

Progress depends in no small extent on ensuring the continued and sustained renewal of the intellectual resources at the heart of the creative process—the dedicated, highly educated, creative scientists that determine the success of these endeavors. Regrettably, there is a trend in our country of the "brightest and best minds" leaving biomedical sciences for careers that appear more challenging and a more important part of our nation's future. This trend must be reversed.

Patient-centered research merits careful attention because it is the link between laboratory discoveries and the advances in prevention, diagnosis and treatment that improve medical practice and the quality of life of patients and their families. This transition is currently threatened by the practices of various health care management companies and by the payment practices of insurers. Further, the nominal support provided by the NCI to this endeavor—less than 10 percent of NCI's total budget—is causing many talented clinical researchers to go the way of the dinosaur as they are forced away from research and into clinical practice.

Investigational therapy administered under the aegis of a fully approved clinical trial is often the best therapy available to many patients. It is important that patients not be denied access to clinical trials. The knowledge gained through these studies is important to progress, and the treatment offered may represent the best alternative available to the patient participants. Both patients and research suffer when health insurers will not reimburse for routine patient care costs in clinical trials. This is compromising our capacity to translate research from the laboratory bench to the bedside. The NCCR supports legislative efforts to ensure third-party payer's coverage of patient-care costs in clinical trials.

We respectfully request that direct funds to cancer research to open the doors for researchers to find and make available for patients new methods for the prevention and treatment of cancer.

PREPARED STATEMENT OF THE JOINT COUNCIL OF ALLERGY, ASTHMA, AND IMMUNOLOGY

The Joint Council of Allergy, Asthma and Immunology (JCAAI) is pleased to submit public witness testimony in support of fiscal year 2000 appropriations for allergy, asthma and immunology programs supported by the National Institutes of Health (NIH). These programs are supported primarily in two of the NIH Institutes: the National Institute of Allergy and Infectious Diseases (NIAID) and the National Heart, Lung and Blood Institute (NHLBI). The JCAAI is a professional, nonprofit organization comprised of the American Academy of Allergy, Asthma and Immunology and the American College of Allergy, Asthma and Immunology, and it consists of more than 4,000 researchers and clinicians who are dedicated to providing care for the 50 million Americans who suffer from allergic or immune disorders.

First, we would like to express our appreciation for the tremendous support this Committee has provided to the NIH during the past two years. The leadership has been unprecedented and we commend you for keeping the NIH a priority of your colleagues in Congress. We know that you have been faced with tremendous budget constraints and we sincerely appreciate your making the NIH a priority for funding increases. We urge your continued leadership for NIH and for the allergy, asthma, and immunology programs supported by the NIAID and the NHLBI.

The JCAAI supports the Ad Hoc Group for Medical Research Funding proposal to double the budget for the NIH over the next five years. Our national research enterprise is poised to make significant strides if the necessary funds are available to pursue the scientific opportunities, preserve the integrity of the research infrastructure, and adequately support and mentor physician investigators as the health care marketplace dramatically alters.

ASTHMA AND ALLERGIC DISEASES

Allergic diseases, including asthma, afflict twenty percent of Americans. The term allergic diseases describes a myriad of medical conditions such as asthma, allergic

rhinitis, atopic dermatitis, food allergies and anaphylaxis. Asthma alone afflicts 14 million Americans, the prevalence is on the increase and the associated economic costs of this disease are quite significant.

The NIAID is in the process of renewing the Asthma, Allergic and Immunologic Diseases Cooperative Research Centers. These centers provide an infrastructure and collaborative environment to study the complex problems associated with asthma, allergic and immunologic diseases. An important object of these research centers is to integrate basic and clinical research initiatives to improve the diagnosis, prevention, and treatment of these diseases. Further, these outreach centers seek to treat and prevent asthma or immunologic diseases in underserved populations.

Allergic Diseases.—Allergic rhinitis (hay fever) alone affects as many as 35 million Americans and is the most common chronic disease. Food allergies and food intolerances are also a major problem. Eight percent of children under six years of age experience food intolerances.

Allergic reactions can occur over a spectrum of severity from minor inconvenience to debilitating as with asthma and even potentially fatal in the case of reactions to drugs, venoms or foods. As many as 2 million people experience severe reactions to insect stings every year, and many experts believe life-threatening allergic reactions to food may occur just as frequently.

Research.—A variety of therapies have been developed to treat allergies, but researchers still do not fully understand certain critical aspects of allergies. When an allergic individual comes in contact with an allergen (the allergy-provoking substance), immune system cells produce an unusual type of antibody known as immunoglobulin E, or IgE, which starts the allergic reaction. Researchers are attempting how to comprehend how the immune system recognizes an allergen, why some people have a more severe reaction to an allergen, and what factors, including environmental and genetic, might be responsible for allergic diseases.

NIAID-supported researchers are among the leaders in the study of allergies. For example, they identified the IgE antibody and they have identified the structure of the IgE receptor. By blocking the activity of the receptor, researchers may be able to provide a new therapy for allergies. NIAID-supported research has also demonstrated that DNA vaccines are capable of stimulating an immune response that may diminish allergy symptoms. Such vaccines could provide a more potent, consistent, and convenient treatment than the current therapy of allergy shots.

Asthma.—Asthma is a major health problem. As many as 15 million people in the U.S. have asthma, and the number of people with self-reported asthma increased from 10.4 million in 1990 to 14.6 million in 1994. The actual number of asthmatics may be higher—asthma is sometimes difficult to diagnose because it often resembles other respiratory problems such as emphysema. Children have a 41 percent higher prevalence of asthma than that of the general population and an estimated 4.8 million children under age 18 have asthma. It is the most common chronic disease in children, and it is one of the most common reasons for missed days of school (parents are also forced to miss work to care for their asthmatic child). Recent research has identified that very early exposure to asthma-causing agents, in infancy or prior to birth, may determine a child's chance of developing asthma. Further, clinical and epidemiological data suggest that viral respiratory infections and exposure to allergens are the most important risk factor early in life that may lead to wheezing, prolonged alterations in airway function and chronic asthma.

Asthma is approximately 25 percent more prevalent in African-American children than in Caucasian children, and asthmatic African-American children experience more severe disability and have more frequent hospitalizations than their Caucasian counterparts. In 1993, African-Americans aged 5 to 14 were four times more likely to die from asthma than Caucasians, and those aged to 4 were six times more likely to die from asthma. Asthma is also more prevalent in African-American adults than in Caucasians. Their hospitalization rate in 1992 was 400 percent higher than for Caucasians and their age-adjusted mortality rate was 300 percent higher. The reason for the higher incidence is uncertain; however, lack of access to proper medical care is related to the poor outcomes.

Direct and indirect costs for asthma were an estimated $6.2 billion in 1990, 43 percent of which was associated with emergency room use, hospitalization, and death. Inpatient hospital costs represented the largest single direct expenditure, totaling $1.6 billion, and emergency room use cost another $295 million. In 1993, asthma was the first-listed diagnosis in 468,000 hospital admissions and asthmatic children under age 15 experienced 159,000 hospitalizations (asthma is the leading cause of hospitalization of children).

Research.—Asthma varies from person to person—symptoms range from mild to severe. While there is not a cure for asthma, it can be controlled with proper measures, including medications, learning to manage episodes, and learning to identify

and avoid what triggers an episode. Triggers include controlling irritants in the air—90 percent of children with asthma and half of adult asthmatics have allergies; avoiding excess physical exertion; and managing emotions. Medications consist of anti-allergy drugs, corticosteroids, and bronchodilators.

In August 1996, researchers (Weinstein, et al) published a report that summarized the results of a study to examine the economic impact of a short-term inpatient hospitalization program for children with severe asthma. The program, based in part on programs developed by NHLBI, significantly reduced inpatient and emergency care days for the subsequent 4 years of follow-up. In a study of 59 children, the median of 7 inpatient days the year prior to rehabilitation was reduced to zero (0) days during each of the following 4 years. Emergency care visits were reduced from 4 in the year prior to rehabilitation to zero. The year before rehabilitation, medication charges as a percentage of medical charges was 9 percent; by the third and fourth years of follow-up they were 45 percent of total medical charges.

The NIAID National Cooperative Inner-City Asthma Study has designed new strategies to reduce asthma morbidity and mortality. Through this initiative the NIAID continues to support and encourage research that may lead to more effective prophylactic and therapeutic approaches for controlling asthma and other respiratory diseases. This ongoing study has recruited children ages 4–12 years with asthma, and will test two interventions to assess their capacity to reduce the severity of asthma in children. The first intervention involves informing the primary care physician about data obtained in phone interviews regarding the child's asthma severity, to maximize the care that the physician is providing, and the second involves educating families about reducing exposure to indoor allergens and passive cigarette smoke.

RESEARCH ENTERPRISE

The JCAAI continues to be concerned about clinical research and urges the Committee to continue vigorous oversight in this regard. Over the past several years there have been numerous reports regarding the grave status of our clinical research enterprise. The JCAAI urges this Committee to ensure that the NIH has in place the following: a process for setting broad goals in clinical research; an approach to clinical research training which will maximize the entry of talent into the field of clinical research; and, provide resources for clinical investigators to maintain clinical, laboratory and patient care responsibilities.

SUMMARY

Allergies and asthma are serious health problems, affecting millions of Americans in both acute and chronic forms. Through research supported by the NHLBI and NIAID, researchers and clinicians have learned much about how to diagnose and treat these diseases, but much more remains to be done. The JCAAI requests a 15 percent increase for the NIH in fiscal year 2000 to explore some of the exciting research opportunities that exist in these areas.

Thank you for your consideration of our request.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF OTOLARYNGOLOGY HEAD AND NECK SURGERY

Good morning ladies and gentlemen, Chairman Specter and members of the subcommittee, I am Dr. Michael Maves, Executive vice President of the American Academy of Otolaryngology Head and Neck Surgery (AAO-HNS). I am here this morning on behalf of the more than 12,000 members urging your continued generous support for funding for the National Institutes of Health and the National Institute on Deafness and other Communication Disorders.

As you may know, otolaryngologists or ENT physicians as we are more commonly known, are responsible for treating patients with disorders of the ears, nose, throat and related structures of the head and neck. I would like to begin by thanking you Mr. Chairman, and all the members of your subcommittee for your leadership in securing a 15 percent increase for the National Institutes of Health in the budget agreement passed by Congress last year. It is largely through the efforts of this subcommittee that our goal of doubling funding for the National Institutes of Health over the next five years will be realized.

This morning, I would like to focus my remarks on the remarkable success to date of the National Institute on Deafness and Other Communication Disorders. As Members of Congress, each of you is singularly aware of the importance of communication; it is how you present yourselves and your beliefs to the world; how you

listen to your constituents and debate legislation. We live in a society driven by communication and disorders of those processes present very real social and professional barriers. As Ruth Hubbard, a prominent American biologist observed, "Without words to objectify and categorize our sensations and place them in relation to one another, we cannot evolve a tradition of what is real in the world."

Since its inception in 1988, NIDCD has made great progress toward realizing its unique mission of understanding the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language. The NIDCD has supported researchers who are devoting their careers to finding the causes, cure, and prevention of such disorders, which collectively affect more Americans than cancer, heart disease, orthopedic disorders, or visual problems. Communication disorders never killed anyone—but think of the lives it has touched!

As in politics, much of the work that we do today will go toward benefiting our country's most important assets, our children. While a small part of the funding that this subcommittee provides to NIDCD each year goes to helping today's patients through clinical research, we are struggling to find new, more effective ways to treat the diseases that cause these disorders—and someday, to prevent them altogether. A growing public demand for evidence-based treatment options intensifies our conviction that more patient-oriented clinical research must be supported.

Presently, however, there is a severe shortage of adequately trained clinical investigators within otolaryngology-head and neck surgery. This shortage of investigators inhibits clinical research productivity and slows the rate at which results available from the nation's thriving basic biomedical research efforts find application to the problems of patients served by otolaryngologists and our colleagues in other medical specialties and the communication sciences. Mr. Specter, I urge you and members of your Subcommittee to examine this issue seriously.

As we enter into the new millennium, I often hear of all the concern over the potential problems of Y2k and how our information infrastructure will be ravaged by the turn of the century. Immense intellectual and financial resources have been brought to bear on preserving the communication systems we all enjoy and rely on today. While I am confident the Y2k problems will not be as serious as projected and our information highway will continue to thrive, I am fearful that many of our children with hearing or communication disorders will not realize their full human potential in the new millennium. We have the intellectual resources to address these problems—but adequate financial resources must be put into place to achieve our goals.

At the beginning of the 20th century, our country created an industrial wave that allowed us to become one of the richest opportunistic countries in the world. The physical capabilities of the men and women that created the infrastructure to produce goods and services allowed us to be a world leader and maintain a healthy economy throughout the 20th century. Now, and into the 21st century, our economy will be heavily dependent upon an individual's ability to communicate. Aside from education, without the fundamental communication skills our country's workforce will be seriously hampered throughout the next one hundred years.

Among the most exciting advances the NIDCD has made include understanding the genetic basis of hearing loss and finding ways to alleviate some of the causes. Research on methods of assessing hearing in an infant on the day she is born will make implementation of Congressman Jim Walsh's Newborn Infant Hearing Screening and Intervention bill possible. Collaborative efforts with other agencies result in greater safety and comfort for our astronauts in space, and bring digital technology to creating a new generation of hearing instruments. NIDCD-supported research has enriched our basic understanding of the human voice, and resulted in new surgical procedures to restore voice to those who once could speak only in a whisper.

Although the NIDCD is among the youngest of NIH's institutes, it has made tremendous progress in understanding and improving communication for millions of people. I am here today to urge your support of another 15 percent increase to NIH, and an even larger increase to the NIDCD to expand support for patient-oriented clinical research by physician-scientists. We hope you will seriously consider increasing the budget of the NIDCD to levels appropriate for the magnitude and impact of communication disorders in our society. Thank you and I will be happy to answer any questions you may have.

PREPARED STATEMENT OF JOHN M. CRAWFORD, BDS, PH.D., PROFESSOR OF CLINICAL PERIODONTICS, DEPARTMENT OF PERIODONTICS, COLLEGE OF DENTISTRY, UNIVERSITY OF ILLINOIS AT CHICAGO

INTRODUCTION

Mr. Chairman and members of the committee, I am Dr. John Crawford, Professor of Clinical Periodontics, Department of Periodontics, College of Dentistry, at the University of Illinois at Chicago and I represent the American Association for Dental Research (AADR). I would like to discuss our fiscal year 2000 budget recommendations for the National Institute of Dental and Craniofacial Research and the Agency for Health Care Policy and Research.

The AADR has a membership of 5,300 scientists. Our objectives are to:

—Promote research in the areas of dental and oral diseases;

—Develop better methods of disease prevention and treatment;

—Enhance communications and interaction among investigators to keep the public and the scientific community informed.

NIDR BECOMES NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

After 50 years, NIDR has changed its name to the National Institute of Dental and Craniofacial Research. The new name more accurately reflects the broad research base supported by the Institute and its basic, translational, patient-oriented, and community-based studies. Although a single word "craniofacial" is the focus of the name change, it is a word of great impact. Craniofacial refers to the head, face, and neck, and NIDCR research in this area covers the developmental processes that form the human face and the plethora of diseases and disorders that involve dental, oral, and craniofacial tissues and structures.

Mr. Chairman and members of the committee, I want to thank you for recognizing the expanded work of NIDCR and for initiating the name change.

When people meet, the face is the focal point and its role in communicating through speech and non-verbal signals cannot be overemphasized. The craniofacial region is, of course, essential for other vital functions such as breathing, eating, speech and hearing.

Birth defects of the human face are particularly devastating and have become an area of increased attention. Every hour a baby is born with a craniofacial birth defect. The habilitation of these infants and children costs almost $1 billion each year. Investigators began studying the most common craniofacial birth defect, cleft lip and cleft palate, in the early days of the institute. Today, several hundred genetic conditions are known to produce craniofacial syndromes, and scientists using the techniques of modern molecular biology have identified more than 100 associated regulatory and structural genes. Certain genes involved in craniofacial development have far-reaching effects; they also affect the formation of distant parts of the body, including the limbs and heart.

BACKGROUND

The Dental Institute was born in 1948. The impetus for its creation was the revelation that oral infections were so prevalent and severe that the country's military preparedness was compromised. Congress was shocked that so little was known about the cause of oral diseases.

Now a half a century later, Americans are realizing the benefits of the Federal investment in biomedical research. A revolution has occurred in understanding the human body and mind. Dental scientists have contributed significantly to that knowledge; initially by establishing that dental caries and periodontal diseases are infectious diseases and subsequently translating that knowledge into multiple means of prevention.

Dental scientists have pursued fundamental questions about the form and function of the craniofacial, oral and dental tissues, their genetic origins, neurological controls, and the multiple strategies the body employs for their protection, nourishment, repair, and regeneration. Today, dental science research areas are clustered around genetic, behavioral and environmental factors that result in human diseases; infection and immunity; oral pharyngeal and laryngeal cancers; and biomimetics, tissue engineering and biomaterials to improve diagnostics and therapeutics.

Over the last couple of decades—dental scientists have learned that: "The Face is the Window to the Body."

MAJOR ACCOMPLISHMENTS

Over the past five decades, Americans have significantly benefited from the Federal investment in dental research. This public investment has resulted in dramatic improvements in dental practice, saved billions in dental care costs and created a generation of Americans with the best oral health in the world. Fifty years ago, most people assumed they would be toothless by age 45. The "baby boomer" generation will, however, enter old age with almost all of its teeth. This accomplishment will bring new problems to solve in maintaining these teeth in a healthy condition and free of decay because the elderly have weaker immune systems, lower salivary flow rates and altered diets. The following are a few examples of NIDCR-sponsored research:

1. *Craniofacial, Oral and Dental Tissues as Models*.—While salivary glands, teeth, tongue and taste buds are unique organs, other craniofacial and oral tissues are models of tissues found elsewhere in the body. With that in mind, oral health investigators have begun to conduct basic studies of bone, cartilage, joints, nerves, muscles and glands, and the diseases affecting these tissues. Because pathological processes are so similar and whatever happens in the mouth can affect—and be affected by—disease or disease treatments targeting other parts of the body, NIDCR has become a key player in research on many chronic and disabling systemic diseases.

2. *The Role of Saliva in Defense of the Body*.—Dental scientists established that the fluid that bathes the oral cavity contains antibodies and a multitude of molecules that nurture, maintain and defend the oral tissues. The latest of these molecules to be discovered is SLPI (secretory leukocyte protease inhibitor), which makes it difficult for the AIDS virus to invade immune cells. Xerostomia (dry mouth) results from primary salivary gland disease, head and neck radiation or chemotherapy, as a side effect of hundreds of over-the-counter and prescription drugs and is a particularly troublesome problem for the elderly. Without an adequate flow of saliva, people can experience rampant dental caries, oral abscesses and serious difficulties in speaking, chewing and swallowing.

3. *Infectious Diseases and Immunity*.—It is not surprising that an Institute that early on established the bacterial nature of both dental and periodontal diseases has long supported microbiology research. These studies have grown to cover other oral pathogens such as viruses, bacteria, fungi, and parasites. Risk factors, modes of transmission and the variety of immune and non-immune defense mechanisms the body employs to combat infection are also part of the studies. We now understand that the interaction of oral flora with host tissues determines the state of oral health or infection and this knowledge has moved research away from studies of isolated bacteria to the study of microbial ecology. At the same time, analysis of the genomes of oral pathogens has enabled researchers to determine the key genes that determine a microbe's ability to adhere to and colonize oral tissues and cause disease. Among diseases studied are dental caries, periodontal diseases, oral candidiasis, herpes simplex virus and human papillomavirus infections. Also included is research on immunity, with special emphasis on mucosal immunity and non-immune salivary protective components. The oral manifestations of systemic infectious diseases such as hepatitis and HIV/AIDS and the development of new diagnostics and therapeutics are of special interest. The latter includes transfer to the salivary glands of genes whose products, released into the mouth or into the systemic circulation, are of therapeutic benefit.

4. *Neoplastic Diseases*.—Oral, pharyngeal and laryngeal cancers are continuing to exact a toll of 42,000 new cases and 11,000 deaths each year. NIDCR has seized the opportunity stemming from findings in cancer genetics, the role of oncogenes and the discoveries of tumor-suppressor genes to support a major initiative to combat oral cancers. The numbers of these cancers are small compared with breast, colon and lung cancers, but oral cancer patients suffer disproportionately from severe pain, disfigurement and impairment in key functions, such as swallowing and speech. The disease itself and the treatment both contribute to suffering, and the cure rate for oral cancer has not improved in the last 30 years.

5. *Biomaterials, Biomimetics and Tissue Engineering*.—We are in the midst of a revolution in our approach to repairing and regenerating the body's tissues. This revolution is based on a greater understanding of the molecules involved in maintaining tissue integrity and particularly how tissues remodel after injury. In Biomimetics and Tissue Engineering, the body's own molecules and processes are used to rebuild tissues, and thus avoid introducing metals, plastics or other foreign materials. Bioengineering is a cross-disciplinary and interdisciplinary field of research aimed at enhancing the development of natural and synthetic diagnostics, therapeutics and biomaterials for the repair, regeneration, restoration and reconstruction of craniofacial-oral-dental molecules, cells, tissues and organs.

WHAT NIDCR HOPES TO ACCOMPLISH

Dentistry has indeed accomplished a lot. But we have much work to do to reduce the impact of oral and craniofacial problems on the quality of life of Americans. Investments in science have fueled the engine of technology that improves clinical dentistry and oral health. What should we anticipate from the next 50 years? How should we prepare for the 21st century? We must view our preparation in the context of major changes in demography, disease patterns, management of health care, international emigrations, the global economy and the revolutions in information technology. By the year 2020, the U.S. population will reach 300 million people, and one in every five Americans will be 65 years of age or older.

In this context, the mission of NIDCR continues—to reduce or eliminate inherited, infectious, neoplastic and chronic craniofacial oral dental diseases and disorders. We have formidable, yet attainable, unmet challenges before us.

Investigators are also reporting an association between oral infectious pathogens and premature or low birth weight infants, pulmonary infections and cardiovascular diseases. Thus, we now have exciting preliminary evidence that the mouth not only reflects what is going on in the body but may influence diseases and abnormalities in distant organs like the heart, lungs and the uterus. Investment in further studies may lead to reduced numbers of heart attack victims and premature babies and to reducing the attendant costs of intensive in-patient care for these patients.

BUDGET RECOMMENDATIONS

Mr. Chairman, we support the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in funding for the National Institutes of Health in fiscal year 2000; and specifically we respectfully request $276,518,000 for the National Institute of Dental and Craniofacial Research.

AGENCY FOR HEALTH CARE POLICY RESEARCH

Research supported by the Agency for Health Care Policy and Research (AHCPR) will assist dental practitioners by providing the evidence base for selecting among alternative diagnostic and dental treatments. The integration of dental care with primary care and access to early detection of oral disease remain unresolved issues that are key to addressing the epidemic proportion of oral disease in low-income children.

The AADR supports an increase in funding for the AHCPR to $225 million, an amount that would allow the Agency to expand its portfolio of projects and trials to include those related to bringing the advances of biomedical research into cost-effective dental practice within the rapidly changing health care environment.

Mr. Chairman, on behalf of the dental and craniofacial research community I want to thank you and the members of the Committee for your past support.

This concludes my remarks. I will be happy to answer any questions you may have.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

Mr. Chairman and members of the Subcommittee: My name is Aaron Friedman and I am president of the American Society of Pediatric Nephrology. In my other life I am Professor and Chairman of the Department of Pediatrics at the University of Wisconsin. In that capacity I see patients every day, all of whom are children or adolescents suffering from kidney diseases of one type or another.

In the way of background, the American Society of Pediatric Nephrology, or ASPN, is a non-profit organization that was founded in 1969 to serve as an advocate on behalf of the children and adolescents in this country who must endure the pain and suffering of kidney disease.

Mr. Chairman, I want to take this opportunity to express to you and the Subcommittee our deepest gratitude for your leadership last year in calling upon the National Institute of Diabetes and Digestive and Kidney Diseases to develop a research agenda targeted on the needs of children and adolescents suffering from kidney diseases. In response to that charge, the NIDDK called together a number of experts in the field of pediatric nephrology to help craft a plan for conquering kidney diseases that afflict young people. And out of that effort came what is perhaps the most comprehensive blueprint ever developed in this field.

Who will be the beneficiaries if we achieve our intended purpose? They are the infants, children and adolescents who comprise about 25 percent of our population. They are the 1.2 million children under the age of seven who will develop urinary tract infections that may permanently damage kidney tissue. They are the 300,000

children and adolescents who will undergo evaluation for proteinuria, one of the early signs of progressive kidney disease. They are also the 76,000 young people who will have to be treated for hypertension, a precursor of renal failure and cardiovascular disease, as well as those forms of kidney inflammation that disproportionately affect minorities. And they are the 100,000 who will be treated for diabetes, many of whom will ultimately suffer renal failure and end up on dialysis.

While these young people and their families are our primary concern, it is important to recognize that their suffering does not end when they turn 21. Whatever progress we achieve in curing or treating the young means longer, more productive lives when they reach adulthood. Conversely, whatever we fail to do for these young people results in a lifetime of more extensive and more expensive treatment throughout their adult lives. They will grow up to be among the 300,000 Americans with end-stage kidney disease who require dialysis or a transplant to survive.

But finding cures and effective treatments for kidney disease is more than good social policy. It is sound economic policy as well.

Over 90 percent of patients with end-stage renal disease, and patients receiving kidney transplants are covered by Medicare. Together, the two represent the single largest disease expenditure in the Medicare program. For example, over the four-year period 1991 through 1994, Medicare paid $25.6 billion in claims for end-stage renal disease patients.

Why is it so important to make the distinction between pediatric and adult kidney disease? Because when chronic kidney failure occurs in young people, normal growth and development are impaired. Scientists also believe that chronic kidney failure has a profound effect on the developing brain, often causing learning disabilities and mental retardation.

To address these unique circumstances, pediatric nephrologists are specially trained and qualified to manage the renal diseases that surface in this age group. We have special expertise in the physical and psychological growth and development, pediatric drug dosages, nutritional requirements, and dialysis and transplantation needs of these young people. Because of the ages of our patients, our course of care often spans 20 years, compared to three years for adult patients. We are uniquely qualified to manage the coordinated, multi-disciplinary approach that is required to meet the care and treatment needs of young people. And in contrast to other nephrologists, the vast majority of us train and work at academic health centers and children's hospitals—the places families turn to when their children suffer from chronic kidney disease.

Mr. Chairman, the pediatric nephrology program at NIDDK is the central focus for research in this field. This is augmented by NIAID's work in basic immunology and organ transplantation.

RECOMMENDATIONS

Mr. Chairman, we support the recommendations of the Ad Ho Group for Medical Research Funding, which calls for an overall $2 billion increase in funding for NIH, as well as those of the Council of Kidney Societies. More specifically, it is important that NIH continue to capitalize on both basic and clinical research opportunities that are of highest relevance to the pediatric kidney disease population. To that end, we respectfully recommend that the Subcommittee:

—urge NIDDK to focus additional resources on research into the causes and treatment of chronic kidney disease in children;

—encourage research that recognizes the unique, long-term needs of children afflicted with kidney diseases that may injure the kidney in childhood but eventually lead to devastating illness in adulthood, such as diabetes and hypertension, for example; and

—emphasize the need to expand the number of individuals specially trained to manage the care and treatment of children and adolescents with kidney disease.

Again, Mr. Chairman, we want to thank you for the leadership the Subcommittee demonstrated last year. I would be happy to answer any questions you may have.

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

Mr. Chairman and members of the Subcommittee: My name is Maureen Reagan and I am pleased to have the opportunity to submit testimony on behalf of my family and the millions of families like mine across America who make up the Alzheimer's Association.

In the way of background, the Alzheimer's Association is the nation's largest voluntary health organization devoted to this disease. It is comprised of over 200 chapters and more than 35,000 volunteers working throughout the U.S. to assist families

with respite services, information and referral and caregiver training. Through the Ronald and Nancy Reagan Institute, the Association is making the largest ever private investment in Alzheimer's research—more than $16 million this year alone.

In political circles, Ronald Reagan was always viewed as someone with vision; someone who had the uncanny ability to see, in an unfiltered way, where we as a nation are and where we ought to be. More than fifteen years ago—on September 30, 1983—he issued a presidential proclamation that for the first time drew national attention to Alzheimer's disease. He was moved to do this, in large part, because this relatively unknown disease had stricken four million people; yet most Americans had never heard of it. In that proclamation he wrote that, "The emotional, financial and social consequences of Alzheimer's disease are so devastating that it deserves special attention." As a testament to his vision, he went on to state that, "research is the only hope for victims and families."

If he were here today, Mr. Chairman, I know that my father would want to commend you and this subcommittee for the investment you have made in research over the years. Because of that investment scientists have uncovered the basic mechanisms of Alzheimer's disease and the risk factors associated with age, family history and genetics. They have identified four different genes associated with the disease, as well as more effective techniques for diagnosing it. And the FDA has approved two drugs for treating individuals in the earlier stages of Alzheimer's.

Those advances offer us hope, Mr. Chairman, but not a reprieve. Because whether it afflicts a neighbor who quietly fades behind the upstairs curtains, a relative who no longer comes to visit during the holidays, or a former President, the effects of Alzheimer's disease are drawing closer by the day.

Unfortunately, this problem is not going to heal itself anytime soon. Nor will it age itself away. From now until well into the millenium, millions of baby boomers will shoulder their way into the age of highest risk. Right now, another 400,000 people fall victim to Alzheimer's every year. And unless we find a way to stop it, the four million Americans who now suffer for Alzheimer's disease will grow to 14 million within the next few decades.

There is no way to measure the human costs. But we do know that Alzheimer's disease is draining well over $100 billion a year, mostly from families like ours who care for Alzheimer's patients at home. We know that the lifetime cost of caring for its victims through the prolonged agony of Alzheimer's disease amounts to $1.75 trillion.

To put the problem in a more immediate context, we know that Medicare is spending 70 percent more to care for beneficiaries who have Alzheimer's disease than for those who do not. Absent those higher costs, your job of keeping Medicare solvent would be a lot easier.

Last year, this subcommittee took the bold first step of launching a prevention initiative that puts us on the cutting edge of science. According to researchers, there may likely be ways to prevent Alzheimer's before it takes hold, or to slow its progression enough to keep it from destroying so many Americans in the prime of their lives. And what makes this initiative even more exciting is that we may be able to achieve our goal without developing costly new drugs.

As you know, scientists have found preliminary evidence that readily available treatments like estrogen, vitamin E and anti-inflammatory drugs like ibuprofen may help slow or prevent Alzheimer's disease. This prevention initiative will enable researchers to launch large-scale longitudinal studies of potential treatments, to find those that will delay or prevent Alzheimer's. As a result of your actions last year, in fact, the National Institute on Aging last month launched the first large-scale clinical aimed at preventing Alzheimer's. This particular trial, which is being supported with both public and private funds, is targeted on individuals with mild cognitive impairment. It will test the comparative effects of vitamin E and a drug approved for another use, against a placebo.

RECOMMENDATION

Mr. Chairman, this subcommittee made a down-payment on a prevention initiative by providing an additional $50 million for Alzheimer's research last year. It is vitally important that the effort be sustained. Specifically, we urge you to increase Alzheimer's research by $100 million in fiscal year 2000. These funds would be focused on:

—additional clinical trials of potential treatments;

—discovering biological markers and reliable tests that would allow for earlier detection, so that treatment can begin soon enough to make a difference;

—development of laboratory models to learn how the disease progresses, and test promising therapies without risk to humans;
—testing new methods of treatment and care to improve the quality of life, prevent disability, and develop systems of care that families can afford; and
—better define the epidemiology of Alzheimer's in populations defined by gender, race and cultural background.

In 1986, Mr. Chairman, President Reagan signed legislation creating the federal Advisory Panel on Alzheimer's Disease. After careful study, that panel urged Congress to appropriate $500 million for Alzheimer's research. The $100 million we have requested would fulfill that goal. More importantly, it will help prevent us from losing yet another generation of Americans to the ravages of Alzheimer's disease. Time is running out.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

Mr. Chairman and Members of the Committee: The American Academy of Orthopaedic Surgeons is pleased to have the opportunity to submit testimony in support of increased and sustained funding for the National Institutes of Health, in particular the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

The Academy, an educational organization serving over 16,000 members, is committed to increasing the public's awareness of musculoskeletal conditions, with an emphasis on preventive measures. Its public education programs have addressed such issues as the importance of safety belts, prevention of playground injuries, hip fractures, back pain, recreation programs for the physically disabled, and the critical nature of musculoskeletal research.

Over the past year, the Academy has joined with medical organizations from around the world to launch a Decade of the Bone and Joint, from 2000–2010, for the purpose of raising awareness of the enormous suffering and cost to society of musculoskeletal conditions, and to encourage research and development throughout the world. The project is picking up momentum and the Academy is hopeful that President Clinton will soon sign a proclamation officially declaring the United States as a major player in the "Decade of the Bone and Joint." The Academy also invites the support and participation of this committee. The endorsement of the United States will enhance awareness of the wide array of acute and chronic diseases and injuries that affect the musculoskeletal system, and add momentum to the national and international cooperation necessary to address these challenging, burdensome and costly disorders.

The attention directed to this issue is very timely. As the nation's large population of baby boomers continues to age, countless millions will suffer from a myriad of musculoskeletal conditions. These conditions are omnipresent—striking the young and old around the world. Young people suffer from skeletal deformities, muscular disorders and other developmental abnormalities that persist into adulthood, perpetuating impaired quality of life. At older ages degenerative skeletal diseases, including osteoarthritis and osteoporosis predominate.

Musculoskeletal conditions are among the most frequently occurring chronic conditions affecting the U.S. population. They have a substantial impact on quality of life, use of health care resources, and the nation's economy. They are a leading cause of work-related disability among men and women 16–72 years of age, and are the leading cause of disability among Americans over 65. For example:

Osteoarthritis ranks as the second most common diagnosis, after chronic heart disease, leading to Social Security disability payments due to long-term absence from work. Osteoarthritis is a slowly progressive condition that commonly affects the knees and the hips of over 20 million Americans. It primarily affects cartilage, which is the tissue that cushions the ends of bones within the joint. Osteoarthritis occurs when the cartilage begins to fray, wear and deteriorate. In extreme cases there is complete destruction of the cartilage, leaving bone grinding against bone. It causes joint pain, reduced joint motion, and loss of function. Unfortunately, the causes of osteoarthritis are not yet fully understood and opportunities for more effective treatment remain unrealized.

Research is urgently needed in the following areas:

—Research on the determinants of the progression or natural history of osteoarthritis, relating both to the heterogeneity and the slow, often relentless, evolution of this condition.
—Validation of new technologies being used to assess hip and knee osteoarthritis—such as advanced imaging techniques, arthroscopic examination of joints, and biochemical markers of disease processes.

—Examination of new interventions, many of which may have the ability to alter the rate of progression of this condition. In addition, determining the most appropriate treatment at a specific stage of this disease process needs to be a key area of inquiry.

Surgical replacement of joints has revolutionized the treatment of crippling osteoarthritis. Over 500,000 total joint replacements were performed in the United States in 1997, allowing patients to return to more normal lifestyles. However, because loosening and wear are factors that affect the durability of implants and their fixation, further exploration of this frequent complication is needed. Biochemical studies of implant wear particles have provided insights into the causes of implant loosening and offer the promise of a pharmacologic cure. Pharmacologic agents, in combination with efforts at reducing the generation of wear debris, may lead to novel therapeutic strategies to prevent implant loosening. This could have a profound effect on the longevity of these implants, with a marked reduction in the need for revisions and the suffering that accompanies this deterioration.

Effective treatment of patients suffering from musculoskeletal diseases and injuries increases their capacity for work, ability to attend school, leisure activities and, perhaps most important, improves the quality of their lives. Examples of effective musculoskeletal treatments include joint replacements, as mentioned above, secure stabilization of fractures and methods to enhance the speed and quality of bone repair, correction of foot, hip and spine deformities in children, and significant improvement in the treatment of bone tumors and rehabilitation following surgery. Despite these successes, acute and chronic musculoskeletal disorders still affect large numbers of people.

To improve prevention of injuries and diseases of the musculoskeletal system and care of patients with these problems, musculoskeletal research must be strengthened and expanded.

Scientists stand poised on the border of a new frontier—tissue engineering. Tissue engineering has the potential to solve many currently perplexing musculoskeletal problems. It appears to be only a matter of time before orthopaedic surgeons can fill areas of bone loss and cartilage deficits, even grow actual bone from scratch, simply by providing the right potion of cells, growth factors and matrices.

Tissue engineering is the manipulation of proteins, cells and other biomaterials to facilitate the regeneration of musculoskeletal tissue. This approach is in various stages of development for bone, meniscus, articular cartilage, ligaments and tendons. For articular cartilage, regenerative material is in clinical use, having been approved by the Food and Drug Administration. For other tissues, clinical trials are now underway.

Tissue engineering is a hot topic throughout medicine, but lends itself particularly well to the musculoskeletal system. About 500,000 procedures are done annually in the U.S. to address deficits in articular cartilage. Reliable methods to regenerate joints, if available, would benefit millions of Americans each year. Considerable progress has been made, but additional efforts are necessary to bring these research initiatives to fruition and available to those in need.

Mr. Chairman, crippling musculoskeletal diseases can deprive our children of their normal development and can leave the aging population disabled and dependent on society. A sustained investment in musculoskeletal research funding can really make a difference in our quality of life now and in the future through the development of treatment approaches necessary to cure or alleviate the ravages of musculoskeletal diseases.

Twenty years from now, there will be 10,000,000 more people over the age of 65 than people between the ages of 25 and 50, and by 2030, 2.7 million people will be over 85 years old. That is why in the near future, there will be an even greater need for new technologies to manage acute and chronic health problems. We cannot afford to not invest in our future health. The savings in reduced disability payments, alone, could potentially offset the investment.

The AAOS, therefore, urges the Committee to provide $354 million in fiscal year 2000 for the National Institute of Arthritis and Musculoskeletal and Skin Diseases. We also support the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in the fiscal year 2000 budget for the National Institutes of Health.

Thank you, Mr. Chairman, for the opportunity to present the Academy's concerns regarding the need for additional funding to support research being conducted at the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

PREPARED STATEMENT OF THE GENOME ACTION COALITION

Mr. Chairman and Members of the Subcommittee: Please permit me to thank you for the opportunity to present my views to the subcommittee. My name is Dr. Kay Redfield Jamison. I am a Professor of Psychiatry at the Johns Hopkins University School of Medicine. I am presenting this testimony to you today in my capacity as the Chairperson of the Steering Committee of The Genome Action Coalition (TGAC).

The Genome Action Coalition was created in 1995 by less than a dozen patient groups and pharmaceutical and biotechnology companies. Today, it is comprised of about 135 members. In addition to the patient groups and the corporations, it also counts among its membership most of the professional organizations in the field of genetics, a variety of university research centers and physician organizations, and others.

The fundamental mission of the Coalition is to seek to assure the existence of a political environment within which genomic and genetic research can continue to flourish at all levels.

On behalf of the Coalition, Mr. Chairman, I would like to thank you for this opportunity. The basic message that we are bringing to you today is to encourage the subcommittee to continue its strong support for the National Human Genome Research Institute (NHGRI) to the maximum extent possible, when you are compiling the Labor-HHS appropriations bill for fiscal year 2000.

While we fully understand that your actions must be consistent with sound management and proportional to the increases supplied to the rest of the NIH, we believe that there is a compelling case to be made to place a very high priority on the Human Genome Project.

Mr. Chairman, there are a thousand cliches that I could throw at this subcommittee concerning the promise that is embodied within the Human Genome Project. I know that you have heard them all before. Statements about being "at the dawn of a new age," or "standing at the precipice." And, of course, there is always something to say about the millennium. But, simply put, this is a time like no other in the history of medical research.

The NHGRI, working with the Department of Energy, private industry, and universities, is moving toward the completion of the core mission of the project—sequencing all three billion base pairs that are contained in the human genome. This will present medical science with an unprecedented opportunity. It is an opportunity to move the practice of health care into an entirely new sphere. The era of molecular medicine that the completion of this project will presage will result in advances that we can barely imagine today.

Mr. Chairman, I am wearing a number of hats before you today. As I said at the outset of my remarks, I am a Professor at Hopkins. I am a researcher and scientist. I am also an advocate for persons, like myself, with manic-depressive illness. And, I work closely with the pharmaceutical and biotechnology industries in a number of capacities. All of those are components of The Genome Action Coalition.

One of the strengths of our Coalition is that we work together to address our common interests, choosing to focus on what unites us rather than to dwell on what divides us. And one of the interests that we have in common is our unqualified support for fully funding the Human Genome Project to a level that will enable it to complete its core mission as quickly as possible.

Last year, Mr. Chairman, I believe that many of us in the patient community, and many of our friends in industry, did not do a very a good job of expressing our support for genomic research to you and your colleagues. Many of those who testified spoke only about their immediate interests in other institutes and not about this critical project. Industry was largely silent.

As a result, a serious effort was made in the Senate to reduce funding for this project. Fortunately, with the assistance of this subcommittee, we were able to reverse that process. We brought three Nobel Laureates to Washington and they met with you and other leaders of the Senate committee. And we are very grateful to you for the support you gave us.

Mr. Chairman, there is barely a disease, a disorder, or a condition that will not be affected by the Human Genome Project. I know that you have seen a slide that Dr. Francis Collins, the NHGRI Director, uses. The slide has three pie charts, each one demonstrating the genetic component of a different condition.

The first might be cystic fibrosis and the chart shows mostly genetic cause with a very small environmental component. The second is cancer and there the split between genetics and environment is more even. The third pie chart is AIDS and there the primary causative factor is environment with a smaller genetic component.

The point of this slide, of course, is to visually represent that virtually every disorder, with the possible exception of certain traumas, has a genetic component. Big or small, it is there and it is a factor. As a result of that reality, virtually every disorder will eventually be diagnosed differently, treated differently, prevented differently, and cured differently. This will be the end result of the research that is being undertaken.

All of us in the patient community have immediate concerns and research interests. We want to Child Health, or Heart, Lung and Blood, or Mental Health fully funded because they are doing the research that could have a significant impact today or tomorrow. And I can assure you that we all support and are involved in the effort by this subcommittee and others to double the NIH budget within a five-year period beginning in current fiscal year.

But, I can also assure this committee that the patient community fully understands that the incredible research being conducted at the NHGRI is building the infrastructure that will lead to the long term solutions for all of the diseases and disorders that concern us. There is simply no way that this project can be left behind—unless America wants to relinquish its leadership in biomedical research, increase our trade deficit and retard the progress that we have made in helping our citizens to live healthier and more productive lives.

That is why there is The Genome Action Coalition and that is why more than 130 diverse groups and companies belong to it.

Mr. Chairman, in the past year or two, some in the government and elsewhere have come under a misunderstanding that there is a substitute for completing the international Human Genome Project. Some see a kind of scientific "free lunch" that will enable the government to avoid spending the money needed to bring this project to its goal of sequencing the entire human genome.

Let me be perfectly clear. The private initiatives that have been undertaken into genome research are vitally important contributions to the science. As a scientist and researcher, I am excited about the potential that those plans hold for the treatment of patients. While the methods may be unproven, they are creative and exciting. The simple fact is that every scientific and medical technique in use today was, at one time, unproven.

But, it is critically important to remember that the private plans and the public international plan are different projects done for different purposes. The sequence funded by the NHGRI is checked five times and guaranteed accurate at least to a level of one error in 10,000 base pairs (the actual experience to date has been more like one error in 1,000,000 base pairs). In addition, the sequence that is determined through public funding is made available on the World Wide Web within 24 hours of completion.

The fact that there are private plans developing their own version of the genome, focused clearly on the areas of the greatest potential commercial benefit, is very important. The Federal government cannot, and should not, be involved in drug development. The private plans will make a significant contribution to our ability to develop the next generation of drugs. But, that being said, having the private plans out there actually makes the public plan more important, not less.

Mr. Chairman, as I indicated earlier, the members of TGAC are diverse. Many are opinionated. Some are passionate about issues. We may disagree about where to draw the line on patient confidentiality or intellectual property. But, the sequencing of the human genome is so important, it transcends all of those differences.

This subcommittee is asked to do nothing less than to assure the future progress of biomedical research into the next century. You have an awesome responsibility, one that you have exercised in the past with great foresight, understanding, compassion and talent. As you work toward our shared goal of doubling the NIH budget in five years, on behalf of The Genome Action Coalition I would respectfully request that the funding for the National Human Genome Research Institute be increased by an amount that is certainly no smaller than that of the NIH as a whole.

As always, Mr. Chairman, The Genome Action Coalition and its many members look forward to working with the subcommittee to achieve that level of success again.

Thank you for the opportunity to present this statement to you.

PREPARED STATEMENT OF THE COOLEY'S ANEMIA FOUNDATION

Good afternoon, Mr. Chairman and members of the Committee: It is a privilege and an honor to have the opportunity to address the Committee this year on behalf of the Cooley's Anemia Foundation. I am accompanied by my son Michael, who is now seven years old and is a Cooley's anemia patient.

Mr. Chairman, Cooley's anemia is in some ways one of the great success stories of medical science. Twenty years ago, a child born with this disease had a life expectancy that lasted into his or her mid-teens to early twenties. Today, many Cooley's anemia patients are living into their mid-thirties. That is a source of pride for our community and it is a tribute to the men and women of science who have dedicated their lives to helping these patients.

But with all the progress that has been made, it is important to note that Cooley's anemia remains a devastating and difficult fatal disease. It involves a treatment regimen that is very difficult to maintain. And, it causes a myriad of physical and emotional problems that only get more complex as the patient population ages.

Cooley's anemia is a genetic blood disease that results in inadequate production of hemoglobin, the oxygen carrying, red cells of the blood. This causes a severe anemia that requires frequent blood transfusions throughout a patient's life. But, getting 30–35 transfusions per year is not the most difficult part of the treatment. It is what those transfusions lead to that is so difficult.

The body has no natural way to rid itself of excess iron that results from transfusions. If left untreated, the iron will accumulate in vital organs, particularly the liver and the heart, and will become toxic. The very treatment that these patients need to live will slowly take their lives. It is a terrible irony.

To deal with this problem, iron must be removed and we have a wonderful drug to do that. But, that drug is not like a couple of aspirin you or I take when we have a headache. This drug, known as an iron chelator, must be infused for 10–12 hours per day, every day. It is pumped through a needle inserted under the skin or directly into a vein.

When patients are young, like Michael, compliance can be difficult and painful—for both the child and the parents. Michael is a good boy and he does what his parents tell him. But some day, he will be a teenager and going to a party, or sleeping over a friend's house, or going to a late movie will seem a lot more important than lying down, with that needle stuck in him pumping medicine.

When compliance decreases, medical complications increase. For this reason, it is clear that Cooley's anemia patients need to have an iron chelation drug that can be taken orally, or injected once a day like insulin, or as a nasal inhalant, or in some form other than a 10–12 hour daily infusion. And, to develop such a drug will take time, money and a little bit of luck.

Mr. Chairman, we believe that people make their own luck. We have come to this Committee in the past to request your support for the development of a Thalassemia Clinical Research Network. This Network would be the focal point for Cooley's anemia research. It is a concept that has been used in other diseases; it is an idea that can work for our patients. Several different special emphasis panels have strongly endorsed this approach over the last couple years.

The concept makes sense for a number of reasons. First, such a Network would allow for the pooling of patients, since there is not a research or treatment center in the country that has a sufficient number of patients to do a valid clinical trial by itself. Secondly, the Network would ensure that every clinical study would use common protocols and procedures, increasing the value of completed research and creating greater confidence in the results.

Third, a Network would save money. NIH would not have to conduct individual grant or contract solicitations or competitions nor would it have to hire multiple peer review consultants. They could simply do it once for the entire Network. Finally and most importantly, patients would have access to new therapies sooner because the peer reviewed centers would be able to begin clinical studies without delay when new treatments became available.

Mr. Chairman, I am delighted to report to you this year that the National Heart, Lung and Blood Institute (NHLBI) has now issued a Request for Applications (RFA) to create the Thalassemia Clinical Research Network that we have sought for so long. At this point, I would like to single out the person most responsible for the creation of this network.

Dr. Claude Lenfant has gone above and beyond the call of duty in working with the Cooley's Anemia Foundation and with our Medical Advisory Board to work out the almost limitless number of issues that arise when developing a plan like this. Dr. Lenfant actually took the time to fly to Boston to meet with our doctors to assure that all of the details are in order. His support for this effort will be absolutely key in making it work and we are very grateful to him for his perseverance and commitment.

Finally, Mr. Chairman, I would like to thank you for your strong support. For many years, you and your subcommittee have been a proponent of the research we seek. You have allowed your Committee Reports to stress the importance of progress

in this disease. Your support has represented a turning point in the development of this network and we are thankful for your concern and compassion.

The Network we have sought, of course, is only an infrastructure. It would be meaningless without high quality research to be conducted within its framework. There is certainly no shortage of research available to be done.

There are two issues related to the iron problems that I discussed above that need to be addressed.

First, science must find better and easier ways to remove iron from the body. As I indicated, this is the biggest impediment to successful treatment of our patients.

Second, and also very important, is that we must find better ways to measure the amount of iron stored in the body, particularly in the liver and heart. Liver biopsies are painful, expensive and require sophisticated training and facilities to accomplish. There is no means available to measure iron in the heart. Sound, noninvasive techniques such as MRI or magnetic susceptometry need to be evaluated and put into use if found to be effective.

Steps related to iron are already being taken. Earlier this spring, NIDDK, working in collaboration with NHLBI, issued a Request for Applications (RFA) for both basic and clinical research in areas related to pathogenesis and new therapies for iron overload. The purpose of this initiative is to encourage research aimed at developing a better understanding of the biological consequences of iron overload and improving methods of therapy. A major aspect of this initiative is to elucidate the control of iron transport and metabolism, in order to facilitate the development of improved means of removing excess iron.

The lengthening lifespans of Cooley's anemia patients is creating its own set of issues that cry out for additional research. Now that patients are living into their mid-thirties, issues such as stunted or delayed growth, delayed sexual development or infertility, hormonal levels, osteoporosis and diabetes are all coming to our attention. As a start, detailed studies of the natural history of these disorders are needed. This, in turn, could lead to effective treatment and preventative measures. The psychosocial impact of living with the disease is another critical area of concern.

Detailed studies are needed on the safety and efficacy of fetal hemoglobin enhancing drugs. A break though in this area could eliminate the need for repetitive transfusions. This, in turn, would eliminate the need for iron chelation therapy, as well as further reducing the risk of acquiring diseases from other blood-borne pathogens, such as HIV/AIDS, hepatitis C, and others. The more broadly available this treatment, the closer we would be to relieving the burden of this disease. For the specific form of thalassemia that Michael has, for example, these drugs work very well. For other types, they do not. We need to know why and we need to know how to make them work for all patients.

Finally, Mr. Chairman, no recitation of research opportunities would be complete without reference to the potential for gene therapy. As the Human Genome Project races toward its completion of the sequencing of the genome in the next couple of years, the opportunities to fix the gene that causes Cooley's anemia will certainly present itself. It is critically important that the scientific community is positioned to exploit that opportunity and repair the mutated gene.

Mr. Chairman, the RFA to create the Thalassemia Clinical Research Network was issued by the NHLBI and I have spoken a great deal about their efforts with you today. However, I would be remiss if I did not point out that some of the important research into Cooley's anemia is handled by NIDDK. In fact, the RFA specifically points out that NIDDK and NICHD are potential avenues for funding for some of the research that will take place through the Network.

We at the Cooley's Anemia Foundation are ready, willing and anxious to work with any and all of the institutes at NIH that are interested in our children's specific problems. The level of expertise that exists on that campus and throughout the scientific research community in the United States and in Canada is truly amazing. It is the reason why we continue to have hope for a better future.

Part of that better future, of course, will be realized if this Committee is able to continue the effort it began last year to double the NIH budget over a five-year period. I fully understand the pressures that are placed on this Committee. You are asked to fund some of the most important programs of the Federal government and choosing between medical research, and early childhood education, and worker safety requires great patience and wisdom—and more money than the Budget Committee routinely allocates to you.

But, as you look around this room this afternoon and on all the days of outside witness testimony, I know that you all understand the direct relationship between the decisions you make and the quality of life of someone like my son Michael. Michael is blessed to grow up in a magnificent time in the greatest country on Earth. Open before him is a limitless world of opportunity and choices.

He simply has one challenge that stands in his way. That is the challenge of Cooley's anemia. But today, with the creation of the Thalassemia Clinical Research Network, we are seeing the beginning of the opportunity to scale that mountain. We are seeing the beginning of a new day for these patients. The progress that has been made in the last twenty years has been breathtaking. But it cannot begin to compare to what we are going to do—together—in the next five years.

For that, I thank the Committee and our friends at the NIH and scientists around the country and the world. Together, we will be able to beat this disease and will bring another group of our citizens fully into the mainstream of American life.

Thank you again for the opportunity to appear before you today.

PREPARED STATEMENT OF THE JEFFREY MODELL FOUNDATION, INC.

Good morning, Mr. Chairman and members of the Committee. It is a singular honor to have the opportunity again this year to present testimony to this subcommittee on behalf of the Jeffrey Modell Foundation, which my husband, Fred, and I founded in 1987. I would like to spend a little time in this testimony telling you about our successes, our successful partnerships, and our progress in fighting primary immune deficiency disease. This remains an insidious, still largely unknown, disease. Then, I would like to talk to you about what we at the Foundation see as the major challenges that lie ahead of us.

RESEARCH

Mr. Chairman, as you know, the Jeffrey Modell Foundation does not come around with its hand out, looking for someone to solve our patients' problems. We are vigorous and active participants in the research process. There are several examples and I would like to review them with you now.

First, with regard to the National Institute of Allergy and Infectious Diseases (NIAID), the Jeffrey Modell Foundation is currently co-funding three research projects. These projects are being undertaken at three major medical research institutions as a result of responses to Program Announcements (PA's) made by the institute. The applications went through the normal peer review process and were judged to be excellent. We are currently in the second year of the funding cycle for these grants.

Second, at the National Institute of Child Health and Human Development (NICHD), we have followed the identical process and again, we are funding three research projects. We are in the first year of funding these grants and we are very encouraged that the work that is being done will have a solid impact in advancing the science with regard to primary immune deficiency.

Third, at the National Cancer Institute, last year we discussed the important connections between cancer and inherited immune deficiencies. This Committee included report language last year urging that a symposium be held among NCI, NIAID, NICHD and NHGRI to explore those connections and develop a research plan. We were delighted to read in NCI's budget justification that such a symposium will be held in the current fiscal year and we look forward to working with NCI on it.

In addition, we should point out the key role in this symposium being played by the Office of Rare Diseases (ORD) in the Office of the Director. This small agency, under the leadership of Dr. Stephen Groft, has been exceedingly generous in its financial support for this symposium. We look forward to working with them in the future on the next round of symposia to further understanding and help establish a comprehensive NIH research agenda.

Finally, as you know, we have in the past funded graduate fellows at NHGRI. That institute continues to make remarkable progress in identifying the genes responsible, in whole or in part, for one or more of the 80 different forms of primary immune deficiency diseases. NCI's budget justification cites 75 different genes identified to date and that is happening because of the strong and coordinated effort taking place at the Genome Institute.

Needless to say, Mr. Chairman, with interests in four different institutes (and we could make a case to be involved in a couple more), the Jeffrey Modell Foundation is deeply interested in the entire research enterprise at the National Institutes of Health (NIH) and we hope that the Committee will continue to exercise its strong support. We are disappointed that the Administration's budget includes such a small increase for the institutes for next year and strongly support your efforts to keep NIH on a path to double the funding over a five-year period, beginning in fiscal year 1999.

The National Institutes of Health is one of the great success stories of the federal government. Its contributions to public health, to curing disease, to improving people's lives are well known. But, it also makes extraordinary contributions to the economy, to our balance of payments, and to our productivity. Appropriating funding for NIH is an investment in all Americans.

EDUCATION AND AWARENESS

As you know, Mr. Chairman, as important as our investments in research are to the Jeffrey Modell Foundation, we believe that our true calling, the place where we can have an immediate impact on people's lives is in the area of developing an improved education and awareness of primary immune deficiency diseases among the Congress, physicians, other health care workers and the general public.

Simply put, Mr. Chairman, in addition to the 500,000 diagnosed cases of primary immune deficiency, experts estimate that there are at least another 500,000 cases that remain undiagnosed or misdiagnosed. It is that second group that we are targeting. They are the children who miss school because they are "sickly." They are the ones who sometimes have antibiotics thrown at them, one after another. They are the ones that are draining resources from the health care system and causing their parents to miss work on a regular basis.

We brought the concept of an education and awareness campaign to the subcommittee last year and, as you have always done, you encouraged us to move forward. And we have. I would like to report to you today on what we have accomplished since we were last here, tell you about the help we have had from our friends in the federal government and then tell you about the areas where much more has to be done.

First, let's take a look at the Jeffrey Modell Foundation itself. We have continued to enjoy great success. We have created three education and awareness centers, located in New York, Boston and Seattle and coincident with our Foundation-funded research centers in those same locations. By tying the researchers to the education and awareness programs, we believe that we enhance both programs. The natural relationship between them is strengthened and their effectiveness multiplied.

NICHD, Mr. Chairman, has been a wonderful partner. Under the extraordinary leadership of Dr. Duane Alexander, Child Health has produced a detailed brochure that significantly moves the understanding of these diseases forward. In addition, we are assured that the institute will remain a strong and active partner, willing to commit its resources to additional elements of this campaign.

Just three weeks ago, we met with senior officials at NIAID and I would like to report to the Committee that they too have agreed to join in this effort. NIAID has much to offer to a campaign of this nature. They were the first institute with whom we collaborated on research and one where we have strong ties. We feel fully confident that NIAID's participation will bring a substantial step forward for our efforts.

Another partner in this campaign is the Centers for Disease Control and Prevention in Atlanta. CDC has extraordinary talent in education and awareness campaigns. The Committee adopted report language urging CDC to "collaborate with NICHD to educate physicians, other health professionals and parents about the detection and management of primary immune deficiency diseases."

Mr. Chairman, we are somewhat concerned that perhaps CDC did not fully understand the Committee's intent. As I said above, we have raised precious funds for this project, as we always do. NICHD has already committed resources to this campaign and is willing to do more. NIAID has said that they are on board. But, CDC has indicated to us that they do not have a "funding stream" for this endeavor. Well, we are not experts in government finance. But, it would seem that the agency of the federal government charged with disease control and prevention might be able to find, within its $2.6 billion budget at least as much as a small foundation that raises less than $2.0 million per year for a class of diseases that is undiagnosed or misdiagnosed among at least 500,000 Americans, most of whom are children.

Once again, Mr. Chairman, we are not asking CDC, or any of the institutes of the NIH, or anyone else to do anything that we are not willing to do ourselves. We have spent countless hours meeting with pharmaceutical and biotech company representatives, patiently explaining who we are, what we do, why it matters. By and large, they have been responsive and generous in their support. All we ask—all we have ever asked—is that our government be our partner.

We envision an education and awareness campaign that will truly "move the needle" on understanding this class of diseases. Our efforts will be targeted at doctors, like pediatricians and family practitioners; it will be targeted at other health care

professionals, like school nurses and managed care plans; and, most importantly, it will be targeted at the parents of young children.

The basic message of this campaign will be to say that if a child seems sick more than other kids—if he or she has more than eight ear infections in a year, or two or more serious sinus infections, or two or more pneumonias, or any of the other ten warning signs—maybe there is a problem. At that point, the doctor should consider drawing some blood and looking for a primary immune deficiency.

That simple act could save a lifetime of illness for a young person. Many of these diseases can be effectively treated if they are diagnosed early and they are diagnosed correctly. Prescribing the correct treatment can prevent the long-term damage that occurs when children become sick over and over again unnecessarily. Damage to the lungs, in particular, seems to be cumulative and debilitating.

Related to this point, Mr. Chairman, I should point out that this past year has been a difficult one for many of the half million Americans who rely on infusions of intravenous gammaglobulin. This is the blood component that gives them a chance to stay healthy and, in some cases, a chance to survive.

There has been an unfortunate shortage over this past year and we at the Jeffrey Modell Foundation have worked responsibly to assure continuity of supply by moving with industry, the House Oversight Committee on Blood Safety and the FDA. Our initiatives have enhanced communication and helped build bridges of trust between manufacturers, regulators, specialist physicians, patients and their families. But once again, education is the underpinning of trust and, in this instance, the education is so important as to be a matter of life and death.

Mr. Chairman, the Jeffrey Modell Foundation is dedicated to finding a cure for the primary immune deficiency diseases. We are also dedicated to creating an environment in which children with these diseases are diagnosed correctly, at the earliest possible date, treated appropriately and able to move forward living a healthy and normal life.

This subcommittee, collectively, and its members, individually, have always greeted us very warmly when we have come to Washington. We have been supported in what we have tried to do, we think, because it is right and because we are going about it in the right way. Our message to you this year is that we have made progress in the past year, but there remains a great deal for us to do. If you keep doing what you have been doing—funding research and supporting our efforts—we will keep working on behalf of these children. And together, we will have improved people's lives. Certainly there can be no higher calling than that.

Thank you Mr. Chairman.

PREPARED STATEMENT OF STEPHEN A. SPECTOR, M.D., CHAIR, EXECUTIVE COMMITTEE, PEDIATRIC AIDS CLINICAL TRIALS GROUP

Chairman Specter and members of the subcommittee, thank you for inviting me to appear this morning. I am Dr. Stephen Spector and it is an honor to testify today as a member of the board of directors of AIDS Policy Center for Children, Youth and Families.

AIDS Policy Center was founded in 1994 to help respond to the unique concerns of HIV positive and at-risk children, youth, women and families and their service providers. The Center conducts policy research, education and training for consumers and providers on a broad range of HIV/AIDS prevention, care and research issues. Affiliates include over 500 community-based organizations in 27 states, D.C. and Puerto Rico.

In addition, Mr. Chairman, I am a Professor & Vice-Chairman of the Department of Pediatrics at the University of California, San Diego, and Chair of the Executive Committee of the Pediatric AIDS Clinical Trials Group (PACTG). The PACTG is the leading clinical research group in the world dedicated to the prevention of mother-to-infant transmission of HIV and improved strategies for the treatment of HIV-infected children and adolescents. It is funded through a joint effort of the National Institute of Allergy and Infectious Diseases and the National Institute for Child Health and Human Development.

The PACTG has been responsible for carrying out the studies demonstrating that transmission of HIV from an infected pregnant mother to her infant can be dramatically reduced by AZT treatment, for establishing new treatments for HIV-infected children and for having changed HIV infection of children from an invariably fatal disease to a chronic illness.

I appreciate the opportunity to discuss the method(s) by which the National Institutes of Health allocates resources among the many disease research priorities and opportunities. In the broad perspective, there are fundamentally three different cat-

egories of research that require support: basic science, studies of pathogenesis or translational research, and clinical research including clinical trials, epidemiology, behavioral and social science research. I would like to spend a few moments discussing each of these areas.

Basic research is the driving force behind new advances and most importantly new conceptual breakthroughs in biomedical science. By its very nature, it is unpredictable. By exploring what is unknown, basic research challenges what is known and questions long held dogma. It is most responsible for having revolutionized science in the twentieth century and will certainly impact on every facet of our lives in the centuries to come. Perhaps most importantly, the implications often cannot be predicted and frequently lead to significant benefit in areas far afield from the intent of the original research.

As basic research has become more complex, the challenge is often to recognize the potential implications of basic research to questions specifically relating to human disease. This research, most recently termed translational science, extends the findings of basic science in an attempt to understand how a disease is caused or to how an illness can be identified or monitored. It attempts to understand why patients have the symptoms that they do. Translational research often generates questions and important new approaches for clinical researchers. Thus, translational research bridges the gap between basic science and clinical research.

Clinical research evaluates novel approaches for the detection, treatment or prevention of disease. The best clinical research is tightly linked to basic and translational research. Importantly, clinical research not only develops new treatments and prevention strategies, but also generates new questions that must then be examined by laboratory based scientists. Clinical research often, like basic science, overturns dogma in its search for the truth.

An important quality of research at the basic, translational and clinical level is that often what is observed in one area has broad implications for other areas of human disease. Researchers from multiple disciplines must be encouraged to cross boundaries in order to provide the scientific synergism necessary to solve complex problems. Additionally, the ability of scientists to rapidly transition from basic research to clinical application provides the greatest opportunity for preventing and treating human illness. This is particularly true for research involving AIDS and HIV. For example, the ability of chemists to isolate protein crystals enabled researchers to identify the crystal structure of the HIV protease. With knowledge of the crystal structure, drugs were developed that specifically inhibit the HIV protease. These drugs have formed the cornerstone for new combination therapies that have significantly slowed the progression of HIV-related disease in adults and children.

Moreover, these drugs have often reversed the immunologic defects caused by HIV infection. In HIV-infected children, as their immune systems have improved we have come to a surprising realization. That is, we do not know in many situations what constitutes the normal immune response of healthy children. Thus, in order to evaluate the reconstituted immune system of HIV-infected children, we will also learn what constitutes a child's normal immune response. This knowledge will help us to better treat childhood cancers, congenital immune deficiencies, premature infants as well as others. Additionally, as potent combination treatments for HIV-infected individuals have become available, these same treatments are being given to HIV-infected pregnant women. Preliminary findings suggest that these new treatments are more effective than AZT alone in decreasing the transmission of HIV from a pregnant woman to her infant.

In addition to providing new knowledge of the normal immune system of adults and children, drugs that have been developed for treatment of HIV infection and its complications have also found uses for treatments of other infections including hepatitis B, hepatitis C, cytomegalovirus, herpes simplex virus and others. Patients with cancer, patients receiving transplants (including heart, lung, liver, kidney and bone marrow), patients with genetic disorders (such as those with sickle cell anemia), patients with diseases of the central nervous system (such as those with Alzheimer's disease, dementia and multiple sclerosis) have benefited from advances made by AIDS research.

How NIH allocates resources among the many disease research priorities and opportunities is multi-factorial and must provide room for flexibility such that NIH is able to take advantage of emerging research opportunities and to fund the highest caliber research. This must be done within the context of responding to public health needs and to taking advantage of those opportunities that have the highest likelihood of success while continuing to explore areas requiring fundamental advances. Additionally, the world looks to the leadership of the NIH to provide new scientific insights and approaches to the treatment and prevention of diseases in-

cluding tuberculosis, parasitic infections and AIDS. We are a global society and NIH funded research must reflect global diseases. There is no road map for science so that many different approaches often involving many different disciplines is required to address the most challenging questions. Even then, the fundamental breakthrough often comes from totally unrelated projects and insights.

As a biomedical researcher and a pediatrician who specializes in infectious diseases, I am concerned by the suggestion of some that a mathematical formula could be used to determine research budgets for specific diseases. These models invariably reduce funding for children and pregnant women. Moreover, they fail to seize the research opportunities that can lead to the rapid development of strategies for disease prevention and treatments. Much has been learned from research that was first performed in children. The advances in childhood leukemia have been applied for the treatment of adult cancers. Similarly, the demonstration that the transmission of HIV from an infected pregnant mother to her infant could be interrupted through AZT treatment led to studies that demonstrated that similar approaches can decrease infection following needle stick exposure and have generated interest in the concept of other post-exposure prophylaxis. Additionally, history has taught us that as an infectious disease declines, if we become complacent and decrease funding for research, there is a resurgence of that infection. The recent resurgence of tuberculosis as a major health problem is one such example.

The multi-disciplinary nature of AIDS requires a coordinated effort. The Office of AIDS Research is a critical component to the successful prioritization and planning of NIH's AIDS research budget. The OAR must have the resources necessary to lead NIH's HIV/AIDS program. The PACTG intends to work closely with the OAR to develop future research priorities and initiatives, including vaccine and other prevention research and international priorities.

Further, AIDS Policy Center for Children, Youth and Families and the National Organizations Responding to AIDS Coalition support increased funding for AIDS research in the context of an overall increase in our nation's investment in research. We support a 15 percent increase for the NIH overall in fiscal year 2000 and a commensurate increase for AIDS research.

In summary, I believe that: NIH must be responsive to Public Health concerns; NIH must fund a broad range of basic, translational and clinical research; and NIH must have the resources and flexibility to take advantage of rapidly changing research opportunities.

Thank you again for the opportunity to speak to the subcommittee. I will be pleased to answer any questions.

PREPARED STATEMENT OF LAURIE FLYNN, EXECUTIVE DIRECTOR, NATIONAL ALLIANCE FOR THE MENTALLY ILL

Chairman Specter and members of the Subcommittee, I am Laurie Flynn, executive director of the National Alliance for the Mentally Ill (NAMI). I am pleased today to offer NAMI's views on the two agencies in the Subcommittee's fiscal year 2000 bill that are of tremendous concern to people with serious brain disorders and their families: the National Institute of Mental Health (NIMH) and the Center for Mental Health Services (CMHS) at the Substance Abuse and Mental Health Services Administration (SAMHSA).

WHO IS NAMI?

NAMI is the nation's largest national organization, 208,000 members representing persons with serious brain disorders and their families. Through our 1,200 chapters and affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious brain disorders such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

Mr. Chairman, for too long severe mental illness has been shrouded in stigma and discrimination. These illnesses have been misunderstood, feared, hidden, and often ignored by science. Only in the last decade have we seen the first real hope for people with these brain disorders through pioneering research that has uncovered both a biological basis for these brain disorders and treatments that work. Research has proven that brain disorders are treatable. The current success rate for treating schizophrenia is 60 percent. The success rate for bipolar disorder has risen in recent years and now approaches 80 percent. For major depression, the rate has climbed to nearly 65 percent. These recent advances would not have been possible without substantial investment in biomedical research directed to the most complex organ in the human body, the brain.

SEVERE MENTAL ILLNESS RESEARCH AT THE NIH

Mr. Chairman, I would like to thank you and your colleague Mr. Harkin for the leadership you have displayed in recent years in bringing significant increases to the National Institutes of Health (NIH) budget. Biomedical research and the NIH are central to improved treatments for severe mental illnesses and ultimately the cure of these disabling brain disorders. NAMI's consumer and family membership is deeply grateful for this bipartisan effort to make biomedical research a top national priority.

At this point, as we come to the close of the Decade of the Brain—an initiative that grew out of the leadership of your former colleagues Chairman Mark Hatfield and the late Lawton Chiles—it is important for us to put into perspective the gains we have witnessed in brain science that have benefited people with serious brain diseases such as schizophrenia and other severe mental illnesses. We also need to plan for the future gains that are so necessary.

I noted earlier that severe mental illnesses are often quite effectively treated. In fact, tremendous advances in treatment of severe mental illnesses occurred during the last ten years, the Decade of the Brain, from the introduction of Prozac and Clozapine, which have virtually revolutionized mental illness treatment. Today, many more consumers, patients with serious mental illnesses, stand able to take charge of their lives, to be productive, to enjoy recovery, because of these treatment advances.

But we should not underestimate how much more must be learned. The brain regions involved in these serious mental disorders, the molecules at the roots of the terrible symptoms, the genes that lead to vulnerability to these illnesses remain to be fully probed. The Decade of the Brain has really only brought us to the threshold of discovery when it comes to brain diseases such as schizophrenia, manic-depressive illness, obsessive-compulsive disorder, and others. We are only now poised to fully probe and finally understand the biological underpinnings of the most serious mental illnesses.

Treatment for mental illnesses, while impressive and comparable to some of the best treatments in all of medicine, are still unacceptable for patients, families, and our society. Many people with severe mental illnesses find only incomplete relief from their symptoms; disability is still all too commonly associated with these illnesses. For bipolar disorder, or manic-depressive illness, treatment works for many much of the time, but not for all and not for all symptoms. Individuals with obsessive-compulsive disorder, a brain disorder we have pinpointed to specific higher regions of the brain, still often fail to achieve much gain in treatment. For children matters are worse because we know so little about the illnesses as they emerge during development, and we know even less about how to effectively and safely treat them.

The national need for severe mental illness research is most starkly demonstrated by particularly terrible statistics. Our nation stands in the midst of a virtual catastrophe: a suicide epidemic. Suicide is the eighth most common cause of death in this country and the fourth most frequent cause of life lost under age 65. Rates are increasing among young men and the elderly. As it stands, 30,000 Americans will die by suicide this year, most of whom have a serious mental illness. The most severe mental illnesses—schizophrenia and bipolar disorder—disproportionately lead to suicide. Ten percent of the 2,000,000 U.S. citizens with schizophrenia are taking their lives; about half will make a suicide attempt at some point. Fifteen percent to 20 percent of the approximately 2,000,000 Americans with bipolar illness will die by suicide.

That severe mental illness research ought to be a priority for our nation is also demonstrated by data from the World Bank and World Health Organization. Severe mental illnesses—major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder—account for four of the top 10 most disabling illnesses in the world. These brain disorders account for an estimated 20 percent of total disability resulting from all diseases and injuries. I hope that this summary of the problem posed by severe mental illnesses convinces you that severe mental illness research must be a priority, especially given the scientific opportunities that exist in the brain sciences. Let me concentrate now on what we think are sound goals for NIH and NIMH, respectively, so that we can bring the full force of our research to bear on this most important health emergency.

NIH INVESTMENT: A CALL FOR INCREASED FUNDING & ACCOUNTABILITY

We applaud your leadership in supporting increases for the NIH. NAMI urges the Subcommittee to follow the recommendations of the scientific community and the

Ad Hoc Group for Medical Research Funding and increase overall funding for NIH by $2.3 billion (a 15 percent boost) for fiscal year 2000.

But increased resources are not the only important objective for NIH: better accountability is also essential. We at NAMI also applaud your efforts to fairly boost NIH funding and limit disease-of-the week approaches to appropriations. Research support at the basic level as well as in diseases is all-important, as is investment in basic technological development and research, in computer sciences and physics, to name but a few. Nonetheless, we urge you to press NIH to invest their resources according to public health need as well as scientific opportunity, as the Institute of Medicine report from last year called for. If NIH is to be in the forefront of the public health improvements that will lead to the most benefit for the people of this nation who support it through their tax dollars, NIH must balance its investment among diseases so that not the loudest advocate or the most connected advocacy group wins research investment, but so that the most disabling and costly illnesses facing the nation are prioritized. Obviously, severe mental illnesses would and should be a top research priority. Yet, based on NIH's own recent estimates, $1.00 is invested in research for every $6.86 in costs of AIDS, $9.96 in costs of cancer, $65.65 in costs of heart disease, and $161.26 costs in schizophrenia. In other words, 15 cents is spent on AIDS research per dollar of costs, compared with 10 cents for cancer, two cents for heart disease, and less than one cent for schizophrenia. This is obviously not a wise research investment strategy for the United States.

Also on the accountability front, we are very concerned that NIH has not developed a consistent definition of neuroscience research and applied it evenly across the institutes. According to our own analysis, which we are preparing to release, it is almost impossible to discern how much the NIH spends on neuroscience research across 20 of its 24 institutes. In short, at the end of the Decade of the Brain we cannot reliably say how much has been spent on neuroscience research—even though it offers tremendous opportunities and is crucial to some of the most disabling illnesses facing this nation. Moreover, NIH estimates of investment in clinical research are also questionable. We urge you to press NIH to develop a more consistent and accurate approach to accounting for its neuroscience investment as well as its clinical research—these are crucial data for you as leading science policy makers as well as for us, who represent those with severe brain disorders whose best hope lies in research.

NIMH: THE KEY TO THE CURE FOR SEVERE MENTAL ILLNESSES

For NIMH, we also applaud this Subcommittee's leadership, demonstrated by your boosting its appropriations significantly in the past few years and by nearly 15 percent in fiscal year 1999, up to its current level of $861 million. This is the year, Mr. Chairman, that NIMH should go over the $1 billion mark. Why? Not only are severe mental illnesses among the most costly facing our nation, as I have described above. Not only does neuroscience offer tremendous opportunities for advances, as is clear. Only with a 18 percent increase in its budget, to $1 billion dollars, would NIMH be able to have a success rate for its reviewed grants of ⅓, funding 754 new and competing grants. The President's budget proposal, which would permit the smallest annual increase for NIH in the past two decades, would only allow for the funding of 455 new and competing grants—a 20 percent success rate. This at a time when NIMH is attracting more research grant applications than any other institute due to the leadership of the institute and the tremendous research opportunities that exist in the neuroscience's and in severe mental illness research. We absolutely should ensure that this time of interest, strong leadership, and research opportunity is taken—so that people with serious brain diseases have the best hope for the future, for themselves and for their families and future generations.

We urge you, Mr. Chairman, to help ensure that NIMH continues its move to spend its tax-payer dollars wisely, with investments in basic neuroscience and molecular biology that will undergird the new treatment frontier for severe mental illnesses and also with strong commitments to serious brain disorder pre-clinical, clinical, and services research. NIMH should continue its efforts to identify genes linked to severe mental illnesses; to fund and expand clinical research into psychotic illnesses, serious disorders in children, and in mood disorders; to continue the probe of the biology of serious mental disorders including schizophrenia, mood, and anxiety disorders. NIMH should also use the tools of behavioral science to better understand the expression and best treatment of severe mental illnesses. But research in prevention and psychosocial research must be aimed at serious mental illnesses. We cannot go back to the days, as NIMH's own advisory council lamented of a prevention research portfolio that by definition excluded serious mental illness research

and instead focused only on social problems such as child abuse, divorce or poor self-esteem so as to improve the nation's mental health. We cannot let another five years and $40 million go to studying children who misbehave while we know so little about serious mental illnesses in children and how to effectively treat these disorders.

We know that serious mental illnesses are brain disorders, are treatable, and are extremely costly—we know the kinds of research that is needed to eradicate these problems. We cannot permit the federal government to avoid addressing these most pressing public health problems in an effort to promote well-being and self-esteem in the population, or, more accurately, to promote full employment of mental health counselors and researchers, while our nation's most disabled citizens with the most costly diseases to the country are ignored.

What research issues are most compelling for our members, the more than 200,000 Americans facing a serious brain disorder? More basic research on the brain and higher brain functioning. More pre-clinical research on the genes, molecules, and brain regions involved in severe mental illnesses. More clinical research aimed at understanding the best treatment for these serious disorders and translating that research into practice. More research aimed at finally better understanding and treating these brain disorders in children. Research aimed at diminishing relapse and disability in severe mental illnesses. More research on how people with severe mental illnesses best receive treatment and services. An accountable and responsible research investment strategy that will help the nation's individuals with severe mental illnesses and their families, as well as the country at large, which must shoulder the burden and costs of these illnesses.

SAMHSA & CMHS

Mr. Chairman, in addition to urging the Subcommittee to support increased funding for brain research, I would also like to note the importance of federally funded mental illness services through the Center for Mental Health Services at SAMHSA. Federal support for community-based care is a critical resource for people with the most severe mental illnesses. With many states reducing their psychiatric hospital beds and a growing number moving toward managed care systems, the federal investment in community-based care continues to grow in importance. For example, funding for the Mental Health Block Grant (MHBG) now constitutes nearly 40 percent of all non-institutional services spending in some states.

In the President's fiscal year 2000 budget proposal, a 24 percent increase is proposed for the MHBG (up from its fiscal year 1999 appropriation of $288.8 million to $358.8 million). MHBG funding has remained frozen since fiscal year 1992. Since that time, we have witnessed the continued widening of gaps in the public mental illness treatment system in many states. The consequences of these emerging cracks in the service system are readily apparent, not just to NAOMI's consumer and family membership, but also to the public: the growing number of homeless adults on our nation's streets who receive no treatment services, well publicized tragic incidents involving individuals with severe mental illness who are not accessing adequate treatment services and the growing trend of "criminalization" of mental illness and the stress it is placing on state and local jails and prisons.

The causes of these growing gaps in the services are varied and complicated: the trend toward privatizing state Medicaid programs through contracting with private managed care firms, cuts in Medicaid Disproportionate Share Hospital (DSH) funding and expansion of the mission of public mental health programs beyond serving the most severely disabled consumers. Moreover, in recent years state mental health agency budgets have been under increasing pressure as a result of forces beyond their control. Among these forces are restrictions on eligibility for SSI and SSDI for people whose disability is based in part on drug abuse or alcoholism and a 1997 U.S. Supreme Court decision allowing states to commit sexually violent predators to state hospitals. NAMI therefore believes that this increase in funding for the MHBG is long overdue.

In addition to supporting the Administration's proposed increase, NAMI further recommends that the Subcommittee target all additional funds for the MHBG in fiscal year 2000 to state and local evidence-based, outreach-oriented service-delivery models for persons with severe mental illness in the community. In particular, NAMI urges that any increase in MHBG funding be directed to assertive community treatment, including the Program of Assertive Community Treatment, or PACT. PACT programs use a 24-hour, seven day-a-week, team approach that delivers comprehensive treatment, rehabilitation and support services in community settings. High-quality PACT programs are typically implemented at a cost that is significantly less than placing an individual in a jail, a residential treatment program or

a hospital. PACT is especially effective in serving persons who are the most treatment resistant, persons with a co-occuring mental illness and substance abuse disorder and persons who are high users of inpatient hospitalization services.

In addition, NAMI recommends that the Subcommittee consider requiring states to report an unduplicated count of persons served by diagnosis, age, and services consumed using the targeted initiative MHBG funds.

NAMI is also concerned that the Substance Abuse Treatment and Prevention Block Grant is not currently supporting programs serving persons dually diagnosed with mental illness and addictive disorders. Evidence-based research, as confirmed by the NIH, verifies that integrated treatment, as opposed to parallel collaborative or sequential approaches, is the most effective model for serving persons with a dual diagnosis. NAMI therefore recommends that the Subcommittee direct SAMHSA to allow states to use funding from both programs to promote integrated treatment services for persons with co-occuring mental illness and addictive disorders.

NAMI is pleased that the President's fiscal year 2000 budget includes a proposed $5 million increase for the PATH program (up from its current $26 million, to $31 million). PATH is a formula grant program to the states to support local programs serving homeless persons with severe mental illness. This increase in PATH funding will help communities all across the country increase access to treatment and supports for the growing number of homeless with severe mental illnesses.

Finally, with respect to CMHS's Knowledge, Development and Application (KDA) program, NAMI would like to cite the important work of the agency's Survey and Analysis Branch in helping to assess the impact that changes in our healthcare system are having on persons with severe mental illnesses and their families. The growth of family education and peer support over the last decade has undoubtedly made a significant contribution to the reduction of inappropriate hospitalization and substantial long-term savings to the nation. Given the insufficient level of housing and rehabilitation opportunities at the community level, NAMI believes that CMHS can and should be doing more to support the role of family as caregiver. This crucial investment in our public system can and should be continued through family and consumer outreach as an essential use of CMHS's KDA resources.

Moreover, in our rapidly changing healthcare environment, it is becoming increasingly important for people with serious brain disorders and their families to serve as monitors of adequate and high quality treatment-especially in the area of Medicaid managed care and the reconfiguration of the public mental health system in many states. NAMI believes that CMHS should use its resources to assist consumers and families to fulfill this important role.

CONCLUSION

Mr. Chairman, thank you for the opportunity to offer NAMI's views on fiscal year 2000 funding for programs of critical importance to people with serious brain disorders. NAMI looks forward to working with you in the coming months to educate both the general public and your colleagues in Congress about the critical importance of investment in biomedical research.

PREPARED STATEMENT OF TERRIE COWLEY, PRESIDENT, TMJ ASSOCIATION, LTD.

On February 25, 1999, you will conduct the Appropriations Subcommittee hearing on the National Institute of Dental and Craniofacial Research (NIDCR) budget. For the past two years, you have responded to the needs of the temporomandibular joint (TMJ) patients of this country by inserting report language into the NIDCR budgets. The Senate has done this for the past five years. As an organization that represents TMJ patients of this country, I would like to brief you on the progress made on this disease/disorder at the NIH as we see it.

Since the Congressional Hearings of June 4, 1992, entitled "Are FDA and NIH Ignoring the Dangers of Jaw Implants?", several important events have taken place. In 1993, the NIDR sponsored the First International Workshop on TMD, steps were taken to plan a Technology Assessment Conference on the Management of TMD which was held in 1996, and in 1995, a RFA in the amount of $1,770,000 was directed toward basic research of TMJ diseases/disorders. The planning of these events took place before Dr. Slavkin became Director of NIDCR.

The events of the past seven years have conclusively demonstrated that there is little science to explain the etiology and pathogenesis of TMJ, and little scientific basis to treatments being recommended to the over 10 million TMJ patients of this country. What is worse, many of these treatments have actually caused a TMJ problem or worsened an existing one. Even the epidemiology of this disease/disorder is deficient. The NIDCR says that "over ten million people" have TMJ. Dr. Slavkin

said to me, "we don't know whether it is twenty million people over ten million, or two." Congressional report language has requested several areas of action to be taken by NIDCR. They are:

THE FORMATION OF AN INTERAGENCY COMMITTEE TO DEVELOP A SHORT- AND LONG-RANGE STRATEGIC PLAN FOR TMD RESEARCH.

After three years of Senate and two years of House report language directing NIDCR to form an intra-institute, inter-agency committee to develop short and long-range strategic plans for TMJ research, a meeting finally took place on July 14, 1998. A second meeting was scheduled for September 11th, then rescheduled for October 14th. That meeting was then canceled. We have not been notified of any further meetings. My inquiries regarding the status ranged from "we have a new person heading that up" to "we have to put our efforts into formulating a response to Congress."

Several original members of that committee have contacted me concerning the lack of action. This inactivity is preventing other agencies from initiating programs, which could lead to improving health care for TMJ patients of this country. One example, the Chief Dental Officer of HCFA told me that until we have a clearly defined and implemented research agenda, they are unable to develop policy on treatments. He conveyed to me his frustration that he had to move this issue to the back burner. He went on to say that he had received a positive response from his superiors and would be willing to collaborate with the NIDCR. We respectfully ask Congress to ask the Administration for Health Care Policy & Research for information on the per-patient cost of TMJ treatments and to conduct an analysis of the efficacy of these treatments.

One reason this is so important is that TMJ is not a specialty of the American Dental or Medical Associations. Thus, there are no standards for dental, medical or continuing education. Treatments abound based on belief, not scientific evidence and, let me emphasize many treatments cause a TMJ problem or can exacerbate an existing one. TMJ is excluded from most dental and medical policies and treatments are extremely expensive.

Another example, Dr. John Watson, Deputy Director of the Heart, Lung and Blood Institute and a founder of the Bioengineering Consortium at the NIH, would have enlisted all bioengineering resources to initiate development of state-of-the-art devices for TODAY'S patients. We have many patients facing total joint replacements with devices that lack evidence of safety and efficacy and are basically 1940's technology. TMJ patients have experienced what one scientist called "the Great American Medical Disaster." They may well be facing another, or living an ongoing disaster. Congress could ask the NIH Director to implement a mission-oriented program for the research, development and evaluation of implants for treating TMJ diseases/disorders, particularly for TODAY'S patients.

NIH IMPLANT PATIENT STUDY

The NIDCR implant patient study was to have been started by the beginning of the Technology Assessment Conference (April 1996). It finally did get underway in 1998 after much prodding by this organization. Unfortunately, the perception we have of this study was confirmed when I was told that the person directing the study recently admitted that he "didn't have a clue what he is doing."

Considering the intellectual and scientific resources available at the NIH in immunology, arthritis and connective tissue diseases, with the Cancer Institute conducting research on breast implant patients, could they not have enlisted experts from outside the NIDCR? This would have been a great opportunity for the Bioengineering Consortium to investigate this device failure. Learning about particle disease would be of value in assessing devices used in every part of the body. TMJ implant patients are experiencing systemic and craniofacial problems that defy medical knowledge. Many have surrendered to the thought that these materials will eventually kill them. Yesterday, the husband of a Silastic TMJ implant patient told me his wife had salivary gland cancer. We cannot say the implants caused the cancer, but how do we know they didn't unless we conduct studies? Congress can request an update on this study, with emphasis on how this study will help the many TMJ implant patients, how soon, and in what manner.

FOLLOW THE RECOMMENDATIONS RESULTING FROM THE NIH SPONSORED TECHNOLOGY ASSESSMENT CONFERENCE

To my knowledge, there has been no PA, RFA, RFP, or training grants in the area of TMJ disease/disorder research as a result of these recommendations. The grant portfolio is scientist initiated, thus, the patients are at the mercy of those scientists

who are already familiar with the field. Originally, Dr. Slavkin stated that NIDR needed money. The following year, they needed better scientists to be enticed into the field because they were not receiving qualified grants, the next year all institutes of NIH received money and so scientists would go to institutes other than Dental and having money wasn't the issue. Each year, we are presented with another reason for not seeing TMJ research "take off" in a comprehensive, yet focused manner with those outside the TMJ field bringing their expertise to this area. I request that you once again direct NIDCR to develop short and long-term research plans with measurable goals, mandated annual updates and annual progress reports to Congress.

EDUCATION

Last week, a TMJ patient of one year called three times in one day. She cried and sounded extremely weak. I suggested she call the NIH for further information. When she called the second time, her voice quivering, she asked if there were words to use other than TMJ, for "you know how demeaning everybody acts when you say you have this." It is imperative that the HHS/NIH educate the medical professionals and the public as to the realities of TMJ. Only when the stigma is lifted from this disease will the patients and their loved ones know the respect and dignity they deserve. It is only then that they will admit to having "TMJ." While on the subject of information, the material the NIDCR sends to TMJ patients is pathetic comparable to information on other diseases within their turf. When I questioned someone about updating the TMJ package, I was told it wasn't high on its priority list. Perhaps NIDCR and The TMJ Association would collaborate in preparing informational material for patients, professionals and the public.

Congressmen, I think that Dr. Slavkin has done a remarkable job of bringing respectable science to our Institute. However, regarding TMJ, there have been too many high sounding words and promises followed by literally no action. I think it is time that Congress and Senate stop asking and begin directing NIDCR to heed report language. It has almost become a game to see how many years they could avoid accountability and responsibility. It is way past due that they took your directives and the needs of TMJ patients seriously.

The TMJ Association and the "over ten million" TMJ patients of this country thank you for responding to their needs over the years by inserting report language into the NIDCR budgets. Your aggressive directives for action will help to improve the health care and quality of life of TMJ patients in this country.

PREPARED STATEMENT OF SUSIE NOVIS, PRESIDENT, INTERNATIONAL MYELOMA FOUNDATION

Mr. Chairman, thank you for the opportunity to present the views of the International Myeloma Foundation in support of funding for multiple myeloma research at the National Cancer Institute and the National Institutes of Health.

MULTIPLE MYELOMA: AN INCURABLE CANCER

Multiple myeloma (FM) is an incurable cancer of the plasma cells of the bone marrow affecting approximately 50,000 Americans. MM patients experience bone fractures, particularly in the vertebrae and hips, and continuous, degenerative symptoms of bone loss that ultimately leads to death. Additional complications include kidney failure, severe anemia, pneumonia, shingles, and, in advanced cases, physical disability.

In 1997 there were 13,800 new diagnoses of MM, representing an average incidence of 4 per 100,000, and 11,300 individuals died. Patients live an average of three to five years after diagnosis, although some survive for significantly longer time. The five-year survival rate of MM patients for the years 1974 to 1976 was 24 percent. In the period between 1986 to 1993 the five-year survival rate was 28 percent, suggesting that little progress has been achieved.

No categorical causes of MM are known. As the incidence and mortality rates continue to climb, we have observed that the populations affected by MM are also changing. Long associated with aging populations 65 and older, the demographic of the disease continues to get younger. At least 10–15 percent of patients are now 45 years or younger. The incidence rates are 50 percent higher in males than females, but evidence suggests the rates of female incidence are rising.

Myeloma incidence may be linked to prolonged or excessive environmental exposures. Recent evidence suggests a possible link to viruses. Research has found that MM is more prevalent in western industrialized countries. Within those countries,

higher rates of occurrence have been observed in coastal, industrial zones, agricultural belts, and in areas with high concentrations of population. In other words, as the world becomes more industrialized, it is not illogical to assume that rates of MM incidence will rise accordingly.

THE INTERNATIONAL MYELOMA FOUNDATION: PUTTING PATIENTS FIRST

The International Myeloma Foundation (IMF) was founded in 1990 by Brian D. Novis, a multiple myeloma patient who had been diagnosed in 1988 at the age of 33. Like virtually all patients, the first time he heard about the disease was when he was diagnosed. Among his greatest frustrations was a lack of access to knowledge about the disease and specialists. So he responded by trying to correct the problem by founding the IMF with the help of other patients, doctors, and researchers who were interested in the field. The first, and in many ways, still the most important, project of the IMF was the establishment of a toll-free hotline that provided information to patients and family members when they most needed it.

The IMF has grown from a grassroots response to the lack of information available about MM to become the foremost resource about the disease for patients and doctors alike. In 1992, the IMF hosted the first worldwide clinical conference ever held for MM specialists. The results of that conference led to the initial publication of Myeloma Today, which, at the time, was the only periodical focused exclusively on MM research and patient issues. That year also marked the death of the IMF's founder, Brian Novis, at the age of 37, just four years after his initial diagnosis.

Now in its ninth year, the IMF has a membership of more than 50,000 individuals worldwide with more than half in the U.S. Over the past five years, the IMF has conducted 20 Patient/Family Seminars to provide individuals access to the latest knowledge and the foremost experts. The most recent, held April 10, 1999 in Atlanta, Georgia, attracted 550 patients and family members from 36 states, the District of Columbia, and Canada. To underscore the difficult access to expert opinions about MM, approximately 90 percent of the attendees had never been to such a meeting before. That, in turn, points out the value of the most important service the IMF provides. Through use of the hotline and mail requests, the IMF sends out—at no charge—more than 1,000 patient information packets per month to every request. In fact, if you are affected by myeloma, you know about the IMF—because it is likely the first source of comprehensive information you ever received about the disease.

An integral part of the IMF mission is to elevate the importance of MM research. In order to encourage new investigators to enter the field, the IMF has funded 14 Brian D. Novis research grants since 1994. In 1998, five research grants worth $200,000 were awarded. This year that figure is expected to rise to $350,000. Most remarkably, these are raised primarily through contributions of $50 or less. Those who know about MM are doing all that they can to help and learn about the disease.

THE NATIONAL CANCER INSTITUTE AND MYELOMA RESEARCH: AN UNFULFILLED LEGACY

Thanks to answers to questions directed to the National Cancer Institute (NCI) by the House Appropriations Committee earlier this year, Mr. Chairman, the IMF believes there is a basis to support more MM research. When asked how many grants in the past five years were focused primarily on MM research, NCI could name none. By its own admission, NCI conducts a "modest program of research related to MM."

Using a conservative approach, NCI estimated that it awarded $11.7 million toward MM research in fiscal year 1999. That figure included $5.4 million for 22 new and non-competing grants with at least 25 percent of the research effort directed toward MM. In addition, NCI stated only 8 of 24 approved, competing grants with at least 25 percent of the effort directed toward MM were funded. These figures need to be put into perspective. MM diagnoses represent one percent of the incidences of all cancers in the United States and two percent of the mortality statistics, yet, as seen above, these percentages are not represented equitably in terms of funding priorities. The fiscal year 2000 budget for NCI will approach $3 billion. However, this is not intended to be an indictment; it is rather a call to action.

MM has specific characteristics that are best investigated by those interested in the field. In order to achieve significant progress in MM research for the benefit of today's patients, substantial increases in funding and other incentives are needed. Today's patients are confronted with the reality of trying to outlive the three-to-five year averages they are told they have to live at diagnosis. Today's patients are confronted by the knowledge that 11,300 individuals—or 31 per day—died of MM last

year. Their hopes for breakthroughs in research should not be limited or penalized because of past neglect by policy makers.

We agree that precise research funding figures are difficult to determine with respect to MM. For example, NCI-sponsored research on the anti-angiogenesis agent, thalidomide, may be extremely relevant to MM but has not been included in the accounting of the MM portfolio. Therefore, the IMF supports granting NCI resources to maintain better data about research relevant to MM and to ensure that information is communicated throughout the medical and patient communities. The IMF is also very encouraged by the present NCI leadership and the forthright approach taken by the Director in soliciting the views of the MM community. That circumstance alone gives us hope.

MYELOMA RESEARCH: OPPORTUNITIES NEEDED

The good news of cancer research—the recent, sustained reductions in overall cancer incidence and mortality rates—are due in large measure to the leadership taken by NCI. Unfortunately, MM patients cannot share in that good news yet. Incidence and mortality rates continue to rise. As NCI rightly stated in its responses to the House Appropriations Committee, "Progress in understanding myeloma has been hampered by a lack of a suitable model for the disease." The IMF believes that NCI must take the lead in determining answers to this basic question.

Among the most significant recent MM research has been the determination of how the myeloma cell behaves to induce bone destruction. The myeloma cell does not, as previously thought, destroy bone directly. Instead it upsets a natural balance of destruction and regeneration that takes place in all healthy bone tissue. It is analogous to the process of peeling skin being replaced by new skin; if that process is unbalanced, the consequences are readily apparent. Similarly, the myeloma cell creates an imbalance that stimulates the cells that induce normal bone destruction and inhibits those that replenish the bone.

An understanding of this process has led to significant understanding of the role of bisphosphonates, a drug category that has been found to restore bone density, in the treatment of MM. The most popular drug on the market, which is administered intravenously monthly in an outpatient setting, is taken by the vast majority of MM patients as a treatment to strengthen and restore lost bone density. The bisphosphonate in the drug acts as an agent to regulate the abnormal function of regular bone destruction and regeneration. Studies of new bisphosphonates may improve the function of existing drugs by 100 percent.

A variety of other, potentially beneficial areas of research that NCI could support to increase its MM research portfolio include:

—Myeloma Cell Biology and Function
—Epidemiology for cancer prevention
—Genetics to develop molecular cancer drugs
—Viruses and possible links to cancer
—Bone Disease treatments including bisphosphonates
—Cell Activation to develop biologic therapies
—Angiogenesis drugs to restrict tumor growth
—Mechanisms to reduce drug resistance
—High Dose Therapy Stem Cell Rescue for transplants
—Immune Enhancement to develop vaccines
—New Drug Development and combinations

MYELOMA PATIENTS: THE PURPOSE OF RESEARCH

Although it would be presumptuous to assume too many generalities without hard research, certain anecdotal trends among MM patients seem to recur with increased frequency. For example, since the mean age for all MM patients is 60, more and more patients are diagnosed just at the times in their lives when they expect to reap the rewards of their life's work. These are people who have lived and played by the rules, paid their taxes, raised their children to become responsible adults, contributed to their churches and communities, and planned responsibly for their retirements. They are overwhelming persons who have made goals and fulfilled plans throughout their lives. The feelings of helplessness they encounter with their diagnosis runs contrary to their normal assertiveness in attacking problems.

Despite the fact no causes for MM are known, the suspected linkages between environmental exposures cause patients to live in tragic uncertainties that something related to their careers or choice of home may have had something to do with their illness. They wonder if by serving their country in foreign wars they may have exposed themselves to the things that cause MM. They wonder if that good job at the refinery may have raised their short-term income at the cost of their long-term

health. They wonder if those afternoons spent planting the crops may have sown the seeds of an incurable disease. They wonder, with new research suggesting a possible linkage between MM and viruses, if they could possibly infect a loved one. They search in vain for definitive answers because the current state of research is too inconclusive to answer their questions.

Another little understood fact about MM is that black Americans are at highest risk among the general population to get the disease. The average incidence rate in the general population is 4 per 100,000; black males and females are diagnosed at rates of 10.8 and 7.2 per 100,000, respectively. MM is the ninth most common cause of death due to cancer in black Americans, representing 2.7 percent of cancer deaths in this population. Of the 59,939 black Americans who died of cancer in 1994, 1,639 were attributable to myeloma, representing approximately 12 percent of all myeloma deaths that year. As with all statistical groupings, black Americans become more susceptible to myeloma as they age, only more so. Black males and females over 65 have an incidence rate of 72.8 and 49.8 per 100,000, respectively. The same rate for white males and females, respectively, is 34.8 and 21.6. No reasonable studies exist to explain this difference.

RECOMMENDATIONS AND REQUESTS

Mr. Chairman, we at the IMF rejoice in the recent advances in cancer research. But our patients and family members become more impatient for results about their disease the more they hear about advances in other fields. They also know the uncertainties about the disease point to real public policy concerns that will have to be addressed at some time certain. It cannot be avoided. And responding to those voices, the message of the IMF is clear: We believe the time has come to direct and increase funding for MM research at the federal level.

The International Myeloma Foundation and its membership support inclusion of funding and legislative report language to grant NCI resources to:

1. review its MM research portfolio;
2. accelerate support of promising research;
3. encourage new investigators to enter the field;
4. convene an NIH-sponsored Consensus Conference to determine the state of MM research and promising opportunities, and to make recommendations to NCI for further research;
5. include sufficient funds to implement the recommendations of the Consensus Conference;
6. integrate epidemiological and occupational health research and data gathering activities relevant to MM to learn more about the molecular pathogenesis of the disease and its suspected agents;
7. provide funding for existing projects approved but not funded by NCI that had at least 25 percent of the effort directed toward MM.

Mr. Chairman, on behalf of the membership of the International Myeloma Foundation, I want to thank you for the opportunity to make our views known about the need for research about multiple myeloma.

We will be pleased to submit any additional information the Committee may require or request.

PREPARED STATEMENT OF DUANE PETERS, DIRECTOR OF COMMUNICATIONS AND ADVOCACY, LUPUS FOUNDATION OF AMERICA, INC.

The Lupus Foundation of America (LFA) represents the 1.4 million Americans who suffer from lupus erythematosus, an incurable, widespread, and devastating autoimmune disease affecting mostly women, with the highest prevalence among women of color. The LFA is the nation's largest voluntary health agency exclusively serving people with lupus and their families. The LFA has 90 local chapters and 500 community-based support groups throughout the United States. Our organization annual provides services to 200,000 individuals.

We want to thank Chairman Specter, Senator Harkin and the other Members of the Subcommittee for your continued support of medical research through the National Institutes of Health. The 15 percent increase appropriated in fiscal year 1999 will increase funding for lupus related medical research from $38 million to $42 million. Even at this higher level, however, many promising studies will continue to go unfunded. The Lupus Foundation of America urges the Subcommittee to do whatever is necessary to keep the NIH budget on the path to double over five years, without causing undue harm to other important health related programs.

The federal government does not have a firm grasp of how much it currently spends on direct outlays to provide services for people with lupus. Based on figures

from a survey of its members, the Lupus Foundation of America estimates the federal government spends several billion dollars annually just to provide disability income payments for people disabled from lupus, in addition to the cost to provide health care through the Medicare and Medicaid programs. When you factor in lost employee productivity, lost wage tax revenue, and the economic burden placed on families, lupus extracts a significant toll on society. Of course, the personal devastation greatly outweighs the financial burdens caused by this disease.

Lupus is an autoimmune disease that, for unknown reasons, causes the immune system to become hyperactive and attack the bodys own tissue and organs. Researchers recognize lupus as the prototypical autoimmune disease. Unlocking the mysteries of lupus opens the door of discovery for many other autoimmune diseases. Lupus and other autoimmune diseases are the fourth leading cause of disability in women.

A market research study conducted for the Lupus Foundation of America estimated as many as 1 of every 185 Americans may have a form of lupus. This was not an epidemiological study. However, it demonstrated that lupus is a widespread disease affecting many Americans.

At the present time, there is no cure for lupus, nor do researchers fully understand what causes the disease. We believe lupus has an underlying genetic basis with an environmental trigger causing disease activity. Recently a team of researchers funded by the NIH narrowed the search for the genes suspected of making individuals predisposed to lupus. This was a significant step forward and this work must continue.

Unfortunately, we still do not know why lupus alternates between periods of remission and periods of disease activity, called flares. We do not know why the disease can remain mild in some individuals and become life-threatening in others. What we do know is that lupus devastates the lives of its victims and greatly impacts on the entire family. Nearly ten million Americans either have lupus or have an immediate family member or close relative with the disease.

Ninety percent of victims are women. Hormonal factors may explain why lupus occurs more frequently in females than in males. However, we do not know if females are more vulnerable to lupus, or if males somehow are protected from the disease. This area of study needs more funding.

Lupus is two to three times more likely to affect African Americans, Hispanics, Asians and Native Americans than Caucasian women. Lupus also appears to be more serious among African American women. An NIH funded study recently identified a gene that researchers believe causes lupus related kidney disease in African Americans. We need to better understand why lupus seems to have a greater impact on women of color. More research will answer this important question.

We also know that lupus most often strikes women in their child-bearing years between 15 and 44. This is one of the most devastating realities of lupus—it destroys the quality of life when those afflicted should be enjoying their best health.

At the present time, there is no single test that can tell if a person has lupus. The disease is particularly difficult to diagnose because symptoms mimic other, less serious illnesses. It is not uncommon for a correct diagnosis to take years. The annual mean cost to provide medical care for a person with lupus ranges between $6,000 and $10,000. However, medical costs can run into the tens of thousands of dollars.

Lupus is not an easy disease to treat or to live with. There is no cure for lupus. Therapies are available to control the symptoms of the disease in a majority of patients, however thousands still die every year from lupus-related complications. Many of the current therapies are highly toxic and can have serious side effects from long term use. For many patients, they must take even more medications to offset the complications caused by the medications taken to treat the disease. More basic and clinical research are needed to identify a cause, develop safer and more effective treatments, and ultimately, find a cure for lupus.

The Lupus Foundation of America urges Congress to double NIH funding over a five year period. Please find a way to appropriate, in fiscal year 2000, another 15 percent increase for the National Institutes of Health, and the National Institute of Arthritis, Musculoskeletal and Skin Diseases. This is the institute primarily responsible for lupus research. Many scientific opportunities currently exist for studying lupus. Promising research proposals await funding—studies that offer hope of finding a cure for this terrible disease.

Additional funding is needed to bring lupus related research to a level sufficient to solve this urgent health problem. We know these funds will be used effectively by the National Institutes of Health to support quality research so lupus patients can live without pain, suffering and the fear of dying.

PREPARED STATEMENT OF DANIEL PAUL PEREZ, PRESIDENT, AND ELIZABETH CONRON, FOUNDING MEMBER, FACIOSCAPULOHUMERAL SOCIETY, INC.

Mr. Chairman, it is a great pleasure to submit this testimony to you today. My name is Daniel Paul Perez, of Lexington, Massachusetts. I am testifying today as President of the Facioscapulohumeral Society and as an individual who has this disorder. As a chief patient activist for the tens of thousands of individuals living with Facioscapulohumeral Disease (FSHD) in the United States, I will continue to argue the case of wanting to live life free from disease.

My testimony is about the profound and devastating effects of Facioscapulohumeral Disease which is also known as FSH Muscular Dystrophy or FSHD, and the urgent need for the NIH funding for research on this disorder. In past years (1994, 1995, 1997, 1998) and again this year we will submit testimony before both House and Senate Committees. We maintain that the NIH and Congress could help cause a significant research and scientific discovery program that, with modest investments, would benefit hundreds of thousands of people worldwide.

The FSH Society has previously informed the members of this Committee of the United States Congress of the need and rationale for research on FSHD. We have updated you on the most recent developments in clinical medicine with respect to FSHD. We have kept you abreast of the latest breakthroughs in the molecular genetics of the disease and given you insight into the difficulty of living a lifetime with this disease.

Thanks largely to your efforts, Mr. Specter, the NIH research funding continues to grow to its current level of 14 billion dollars annually. Those efforts fuel our hope for promising research solutions for FSHD. I must in all candor express our frustration that promising FSHD research support and programs have yet to appear from the NIH, even in light of Congressional mandates and report language for such. While the NIH has seen a funding increase of 30 percent in the past decade, FSHD research through the NIH has not benefited at all. It is most disturbing that FSHD research funding has gone down, not up. Since the FSH Society first testified before Congress in 1994, FSHD research has decreased from between $300–500,000 to between $100–250,000. During this time, Congressional directives to the NIH regarding the state of FSHD research have been either ignored or responded to in an untimely manner. We have met with the NIH officials, testified before the Institute of Medicine Committee and taken the path indicated to put forth our goals. The situation has only gotten worse.

FSHD is a neuromuscular disorder with autosomal dominant inheritance as well as a spontaneously occurring genetic mutation. It has an estimated frequency of one in twenty thousand (1/20,000). Autosomal dominant means that there is a 50 percent chance that a child will inherit the disease from an affected parent. The prevalence could be as much as three times the estimated frequency stated in the literature due to sub-clinical cases. The major consequence of inheriting this disease is that of a progressive and severe loss of skeletal muscle, with the usual pattern of initial noticeable weakness of facial, scapular and upper arm muscles and subsequent developing weaknesses of other skeletal muscles. FSHD can be extremely severe and in some forms can lead to an early death. FSHD can happen to any one of us.

In 1997 the FSH Society, Inc. submitted testimony to Chairman John Porter before the U.S. House of Representatives and to Senator Arlen Specter before the U.S. Senate. We requested appropriations for research on FSHD and the need for Congressional language to the NIH to initiate research in this area.

Report language was issued on July 22, 1997 stating: "Facioscapulohumeral disease—The Committee has heard compelling testimony about facioscapulohumeral (FSH) disease, which causes a progressive and severe loss of skeletal muscle. FSH research includes aspects such as molecular genetics, neurological function and muscular dystrophy involving multiple NIH Institutes. The Committee encourages NIH to take steps to stimulate research in this area and requests NIH to develop a plan for enhancing NIH research into FSH disease, including an assessment of whether an intramural research program in this area would be beneficial."

In 1998 the FSH Society, Inc. again submitted testimony to Chairman John Porter before the U.S. House of Representatives and to Senator Arlen Specter before the U.S. Senate requesting appropriations for research on FSHD and the need for Congressional language to the NIH to initiate research in this area.

In 1998, the NIH finally responded to the 1997 Congressional language: "The NIAMS and the National Institute of Neurological Disorders and Stroke (NINDS) support research on the many forms of muscular dystrophy including facioscapulohumeral disease (FSHD). In 1990, scientists discovered the general location of the defective gene for FSHD on chromosome 4. However, much remains to

be learned about the functional changes that accompany the disease and treatments. In April, 1997, the NIAMS, NINDS and the NIH Office of Rare Diseases, along with the Facioscapulohumeral Society, held a FSHD conference designed to identify medical problems associated with the disease and to help focus research efforts by identifying new research opportunities. As the next step in an effort to increase research interest on FSHD, NIAMS and NINDS are developing a program announcement to follow up on recommendations from the April meeting. NIAMS, NINDS and the NIH Office of Rare Diseases will continue to work closely on encouraging FSHD research and to share relevant scientific advances."

One month after our 1998 testimony before the U.S. House of Representatives, the NIH issued a program announcement that covered, in part, FSHD. PA–98–044 is a response to the 1997 testimony and was over one year after our 1997 testimony. On March 20, 1998, the NIH issued PA Number: PA–98–044, titled: Pathogenesis and Therapy of the Muscular Dystrophies. PA–98–044 was sponsored jointly by the NINDS and the NIAMS and the support mechanisms for grants in this area were the investigator-initiated research project grant (R01) and the program project grant (P01). We were disappointed with the diffusion of our efforts by this program announcement covering not just FSHD but all of the Muscular Dystrophies.

Additionally in 1998, we testified before the Institute of Medicine (IOM) responding to its four-part directive from Congress on priority setting for research at the NIH. We were forced to submit the IOM testimony from the back of the auditorium as it was not wheelchair accessible. We testified before the IOM Committee regarding the area of report language: ". . . We find that the NIH response did not directly address the questions asked by the committee regarding the development of a plan for research in the area of FSHD research and regarding the possibility of intramural research in the area of FSHD research. The response we received did in fact dilute our efforts to accelerate and enhance research directly on FSHD by opening up a program announcement to all of the muscular dystrophies when in fact the request was for FSHD research."

In 1998 report language appeared in three sections of the U.S. House and U.S. Senate Appropriations budget under the NIH, the NIAMS and the NINDS. The report language is as follows:

"The Committee was pleased with the Institutes response to last year's request which encouraged NIH to stimulate research in the area of facioscapulohumeral disease (FSHD). However, the committee notes that NIAMS has not responded in developing a plan for enhancing FSHD research, and has not addressed the question of whether an intramural program in this area would be beneficial. Therefore, the Committee urges NIAMS to conduct a research planning conference in the near future in order to explore scientific opportunities in FSHD research, both intramurally and extramurally."

No response was heard from the NIH in 1998 for the 1998 language. FSHD researchers expressed disbelief both with the lack of funds and with the grants turned down. In 1998, the NINDS and the NIAMS funded no less than $100,000 and no more than $250,000 on direct FSHD research.

This year, the NINDS asked for our ideas/participation on a draft document titled, "Neuroscience at the New Millenium" outlining priorities for NINDS 2000–2001. There was no mention of FSHD or any program that explicitly and suitably covered research on FSHD. My comments to Dr. Fischbach, Director of the NINDS, and Dr. Varmus, Director of the NIH, were:

"I have some comments after having reviewed your document 'Neuroscience at the New Millennium—Priorities and Plans for the National Institute of Neurological Disorders and Stroke fiscal years 2000–2001.' It is clear to me, if not completely black and white, that the formulation of the plan does not account for or even give consideration to FSHD and is not adequate with respect to FSHD.

"Of the greatest concern to me is no direct mention of FSHD in any of the sentences, clauses or paragraphs in the document I received, 'Neuroscience at the Millennium,' despite strong Congressional report language on the issue. I do not see the scope expanding to cover diseases such as FSHD for which there is no known gene—and for which there may never be a gene per se. Where in this program is FSHD covered?

"The NINDS plan is not consistent with recent congressional mandates and report language which instruct NINDS for more involvement in FSHD research. Despite repeated meetings and work with the various institutes at NIH and assurances the responsibility and jurisdiction with respect to FSHD research is shared across institutes; NINDS does not reflect this in the current document.

"Both the House and Senate Appropriations Reports have language for this fiscal year and the last fiscal year that instructs and authorizes NINDS and NIAMS for plans and priorities with respect to FSHD."

In 1999 to date, the NINDS has only one newly issued grant in its portfolio that is directly titled for FSHD. When we called the NIAMS, the secretary who answered incorrectly informed us that the NIAMS does not do research in muscular dystrophy. In 1999, to date, the NIAMS has no grants issued with FSHD in their title. The NIAMS states that it is beginning the process of organizing the research conference for the Spring of 2000 but we have absolutely no indication of movement in this area. The NIAMS again, as it has done in past years, points us toward the Muscular Dystrophy Association (MDA) that has recently started gene therapy trials in limb-girdle muscular dystrophy. FSHD and limb-girdle muscular dystrophy are genetically and clinically different diseases. The NIH must understand that FSHD requires their attention. The NIH must understand that FSHD may be the only muscular dystrophy for which the putative gene has not been identified.

FSHD researchers still express incredulity with the lack of funds and rejection of grants submitted by the top laboratories in the world. In 1999, the NIAMS currently has funded $0 (zero) on direct FSHD research.

Mr. Chairman, it is heartbreaking that with FSHD being a primary neurological disease which is almost exclusively musculoskeletal in its effects, it can not gain support from the very Institutes that have the "neurology" and "musculoskeletal" in their names.

Mr. Chairman, we know that the Committee is overwhelmed in hearing from patient groups such as ours. We know that you trusted that the IOM and the NIH would set its priorities correctly. The truth is that we have come before Congress to testify year after year, given testimony in a wheelchair from the back of the room at the IOM, worked hard to have NIH take a more active, deliberate and responsible role and yet the NIH is not listening to the Congress, the scientific community and the patients on this issue.

Mr. Chairman, this is a clear and disturbing trend. FSH Muscular Dystrophy has a prevalence of 5–10/100,000 persons, Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, has a prevalence of 1–2/100,000 persons and Charcot-Marie-Tooth (CMT Type 1, 2, 3) has a prevalence of 1/15,000 persons. Although FSHD may have a greater prevalence in the population than CMT and be similar in magnitude to ALS, it has received far, far significantly less from the NIH funding sources.

FSHD research may have benefited indirectly from the NIH funding of the Human Genome Project. However, direct funding of FSHD research by the NINDS and the NIAMS at the NIH has been minimal. The total NIH funding for directly titled FSHD research currently for the fiscal year 1999 (fiscal year 1999) is approximately three hundred thousand dollars.

Mr. Chairman, this is clearly inadequate given the recent advances and the high likelihood of making significant progress in the very near future. With a budget of 14 billion dollars, The NIH is spending a miniscule amount on FSHD research. This tiny amount is utterly unconscionable and defies logic and reason given the prevalence of FSHD and the cost of doing molecular genetics research in 1999.

Mr. Chairman, we ask the Subcommittee to earmark a dollar amount to FSHD research. We request that an amount of not less than five (5) million and not more than ten (10) million dollars be earmarked for FSHD research. We know that this Committee does not approve of earmarking. However, the record of five years indicates that the NIH ignores Congressional direction and scientific opportunities. Earmarking appears the only way to get the NIH's attention.

The FSHD community demands that the Congress of the United States of America take action on funding research on FSHD. We are asking today for a promise to people living with FSHD, which commits to funding FSHD research in the following areas:

1. Cloning the gene, characterizing the nature of mutations in the gene,
2. Launching a major effort to understand the normal function of the FSHD gene and how its alteration causes the disease,
3. Conducting natural history studies to provide a baseline for future therapeutic techniques, and
4. Developing therapies based on information in 1, 2, and 3 above.

Additionally, the FSHD community is requesting that Congress ask the NIH to research and make recommendations on the following:

1. Increasing the number of applications received and accepted from investigators working on FSHD,
2. Creating a Center of Research Excellence (CORE) for FSHD research,
3. Enacting intramural NIH programs for FSHD research immediately,
4. Extramural contract programs for FSHD, and
5. Programs to attract and expedite extramural grant applications.

The men, women and children who live with the daily consequences of this devastating disease are your friends, neighbors, fellow taxpayers and contributors to the American way of life. With an historical 88 percent employment rate and an average educational achievement level of 14 years, we personally bear our burden of the health care costs and training expenses to prepare for and maintain financial and personal independence.

We appeal to you today to take our hard earned tax dollars commensurate with our numbers and valuable contributions to American Society. We urge the United Sates Government to allocate a proportion of our tax burden toward research on FSHD.

This is the United States of America and, in a country as great as ours with all of its technical means and ability, it should be absolutely clear that the number one priority for individuals with FSHD and a commanding imperative for the Federal Government is to initiate and accelerate in any way possible, research on FSHD. With modest funding and a clear direction from Congress to the NIH to support research on FSHD significant progress can be made in conquering and eliminating this and other devastating diseases.

Mr. Chairman, again, thank you for providing this opportunity to testify before your Subcommittee.

LIVING WITH FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY (FSHD).

As part of its ongoing mission, the FSH Society, Inc. feels that it is important for Congress and the NIH to fully understand the personal aspects of the disease and to offer help to individuals to empower themselves by educating others about this poorly understood disease. The following is presented by Elizabeth Conron, of Danville, California, who is testifying as the daughter and sister of members of the Board of Directors of the FSH Society, as a founding member of the FSH Society, and as an individual who has this disorder.

"I have FSHD. This diagnosis was a shock to my family and me since no one in our family had been previously recognized to have this disease. Diagnosed at Stanford University at the age of sixteen, I remained physically active until the age of twenty-two. I was a cheerleader, an avid snow skier, captain of my high school swim team and a competitive gymnast. Today, I can only walk short distances with assistance. This disease has affected most of the major muscle groups in my body. I can no longer flex my feet and my shins and calf muscles have atrophied to the point that I can only stand on my outside ankles. My thigh and hip muscles have weakened so that I can no longer arise from a sitting position without assistance and great body contortions. The arch in my back is so severe that I can form the letter C with it. I can no longer raise my arms above shoulder height. I have difficulty with shoulder dislocation. I can no longer feed myself with my right hand. The fingers in my right hand have weakened so severely that I now must learn to be left-handed. My once big and friendly smile has been replaced by crooked, weak lips and I cannot close my eyes at night without taping weights on my eyelids. People stare at my bizarre gait and body contortions. FSHD has replaced and is replacing my once strong and vital muscles with fat. My joints are swollen from the effects of FSHD and my bones with no muscles feel as though they are rubbing together. FSHD is a very painful and disabling disease for me.

My family now knows that my sister and one of my brothers have FSHD as do my mother, two aunts and six cousins. We have watched our family deteriorate physically as one by one we surrender ourselves to wheelchairs. Nonetheless, our spirits remain strong and our mental capacity sharp. We are committed to being productive and contributing members in our communities.

I earned a law degree in 1995, a feat that was truly a physical challenge for me. I stayed focused and worked hard, ultimately earning three American Jurisprudence awards for achieving the highest scores and I served as Student Body Secretary and then Vice President. When the elevator malfunctioned, I hated it. Fellow classmates would carry me upstairs in a piggyback fashion that humiliated me. I was forced to type my exams due to my weakened right hand. Typing was difficult—I used my left hand and only the index finger from my right hand to hit the keys. Despite the difficulties FSHD posed for me, I worked hard to make a contribution to the Law school.

I have two children—four year old Caroline and two year old William. For me, the issue of children and FSHD has caused the greatest hardship. For fifteen years, my beloved and devoted husband and I agonized over the decision to have children. My desire to be a mother would not be denied. My children are adorable and I am a good mother. My inability to do so many things for and with my children causes me grief. When I take my son William to the park, I can not get into the sandbox

with the play equipment due to the wheelchair. I miss the playgroups and birthday parties in other homes due to the lack of wheelchair accessibility. I can not be on a Ferris wheel with my children, supervise them in a swimming pool or walk along a beach with them. Simply combing Caroline's hair is a difficult task. I do not have the arm strength to pick up and hug my children. To receive physical affection, Caroline and William climb into my lap and I drape my arms around them.

Caroline attends preschool and I volunteered to serve as a room mom and work in the classroom. I always look for opportunities to contribute to her well being. I was told that I could injure a child by rolling over a foot with my wheelchair and it was "suggested" that I not go into the classroom. I am the only mother prohibited from volunteering in the classroom.

Often, I lie awake at night and worry about what new weaknesses I will have when I awaken in the morning. I pray that God will stop the progression of FSHD in my body so that I can attempt to adjust to my current level of weakness. As soon as I make the needed adaptations to my life, I weaken again. After thirteen years, we are forced to move since our current home with its narrow doors and hallways is not wheelchair accessible and I can no longer walk in my home. Falling has become a regular event. I have bruised, cut or bent most of my body from my numerous falls and felt it necessary to teach Caroline at age 2½ to dial 911 and say, "Mommy fell and she won't wake up."

I have seen others with FSHD whose basic functions such as bathing and feeding require assistance as well as the use of a wheelchair. Am I emotionally and spiritually strong enough to accept these challenges? I will have a meaningful life. I know that with no treatment or cure for FSHD, I will weaken and not be able to lift my arm from my lap. I will fight against this disease. If you had FSHD, would you not fight to defeat it too? In 1990, I along with a half dozen others with FSHD became the founding members of the national FSH Society. Today, our organization represents over 1,300 families. We are committed to advancing scientific and clinical research and providing support to families and individuals living with FSHD.

Sometimes I watch able-bodied people move about so effortlessly and I wonder if they have any idea how fortunate they are to be able to do such basic things as walk, bend over to tie a shoe, or scratch their heads. I wonder, sometimes, if what is happening to me is just a bad dream. Inside this diseased body is a good person, a young woman who wants so much to be active again. I want to be able to walk with dignity, to catch William as he comes down a park slide, to button Caroline's dress, and to hold my husband in my arms. And I want my smile back.

We are an incredible group of people with a passion to serve our communities and our country. Our drive is limited only by our physical weaknesses. I pray for your help. We need you to help us overcome the devastating effects of FSHD.

PREPARED STATEMENT OF DR. ROBERT A. ALTENKIRCH, VICE-PRESIDENT FOR RESEARCH, MISSISSIPPI STATE UNIVERSITY

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony regarding the National Institutes of Health Institutional Development Award (IDeA) program. I am Dr. Robert Altenkirch, and I am Vice-President for Research at Mississippi State University. I also serve as EPSCoR State Project Director in Mississippi. I submit this testimony on behalf of the Coalition of EPSCoR States.[1]

I would like first to express my gratitude to Senator Cochran for his strong support of the IDeA program and the related Experimental Programs to Stimulate Competitive Research (EPSCoR) in other federal agencies. Senator Cochran has been a strong advocate of IDeA because he understands the importance of enhancing our nation's biomedical research infrastructure by building the research capacity of Mississippi and the other IDeA states. We Mississippians greatly appreciate his leadership on IDeA and a whole host of issues important to Mississippi. We are proud to have him represent us in the United States Senate.

IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103–43). IDeA works to improve our nation's biomedical research capacity by enhancing the capability of states that have not yet substantially participated in the NIH's research endeavors. The NIH has identified the following states as eligible for IDeA funding: Alaska, Arkansas, Delaware, Hawaii, Idaho, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico,

[1] Alabama, Arkansas, Idaho, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, North Dakota, Oklahoma, Puerto Rico, South Carolina, South Dakota, Vermont, West Virginia, and Wyoming.

North Dakota, Oklahoma, Rhode Island, South Dakota, South Carolina, Vermont, West Virginia, Wyoming and the Commonwealth of Puerto Rico. IDeA acknowledges that nearly one-half of the states do not have an adequate R&D infrastructure in the biomedical sciences. Clearly this is not in the long-term best interest of our nation.

IDeA is important, Mr. Chairman, because NIH research funds are extremely concentrated geographically. The 24 states that participate in IDeA received just 5.3 percent of NIH research funding over the fiscal year 1994–fiscal year 1998 period, while the top state alone received nearly three times that amount. The five most successful states combined received 48 percent of NIH funding over the same period.

For example, according to data compiled by the Social Science Research Center at Mississippi State University, Mississippi received $16.2 million in NIH research funding in fiscal year 1998, compared with a national average of nearly $218 million per state. Alaska received just $2.6 million, Idaho received $1.4 million, and New Hampshire received $38.5 million—all a fraction of the national average.

Mr. Chairman and Members of the Subcommittee, those figures are startling. Our country has embarked on a great endeavor: to increase substantially the NIH research budget—possibly even doubling research funding over the next five to seven years. Many scientists and Members of Congress support this worthy goal, and I applaud this important effort.

But while I strongly support efforts to increase biomedical research funding, I think it crucial that all regions of the country participate in this effort—not just existing centers of excellence in a small handful of states. If we are to double research funding we need to enhance our research capacity by including a greater portion of the country in our research endeavors. The 24 IDeA states have fine research institutions that are home to many talented researchers. The institutions and researchers in these 24 states should play a significant role in our nation's effort to expand research capacity; they are crucial to any serious effort to improve our nation's ability to treat, cure and prevent disease.

Yet under the current system these 24 states combined receive just 5.3 percent of NIH research funding. Every region of the country has talent to contribute to our nation's biomedical research efforts—and every region of the country should have the opportunity to nurture and develop their talent pool into individuals and centers that can compete successfully for NIH funding and develop the biomedical R&D base across our nation.

Mr. Chairman, the Congress provided the NIH with $15.6 billion in fiscal year 1999—an increase of some $2 billion from the previous year—and I understand the NIH will likely receive a significant increase this year. Yet out of that $15.6 billion, IDeA received just $10 million—$10 million to be shared by researchers in 24 states to develop the biomedical research capability of almost one-half of the nation.

The Coalition of EPSCoR States is extremely grateful for the support this Subcommittee has provided IDeA thus far. Yet given the size of the NIH research budget and the need to enhance our nation's research capacity, we believe IDeA should be funded at a much higher level—a minimum of $100 million or more.

Building the research capability of the 24 IDeA states is crucial toward the goal of increasing and enhancing our nation's research capability. On behalf of the Coalition of EPSCoR States, I thank the Subcommittee for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION

Mr. Chairman and members of the Senate Subcommittee on Appropriations for the Departments of Labor, Health and Human Services, Education and Related Agencies, thank you for the opportunity to submit testimony on behalf of those suffering from alopecia areata by the National Alopecia Areata Foundation.

Alopecia areata is hair loss. For some people it is the loss of a small patch of hair on their head or some other place on their body. For others it is the loss of every hair on their head, and for still others it is the loss of every hair on their body. While it occurs in over 4 million people, the onset is usually between the ages of 5 and 18. When it strikes it is usually met with shock and disbelief. Most physicians are unaware of its existence, and most people think that they are the only one in the world with the disease.

The National Alopecia Areata Foundation (NAAF) is the largest organization in the world dedicated to finding a cure for alopecia areata. NAAF also provides the most money for research, having provided over one and one-half million dollars for research over the last ten years. The Foundation also provides for a network of support groups, publications on alopecia areata, and an annual convention to share in-

formation, and provide for ongoing support services. NAAF has a website that is open to all and a newsletter to provide information to people who are seeking information on treatments, ideas on coping, and just the simple knowledge that each individual is not alone.

Each year the NAAF office receives phone calls and letters from a wide range of people. Some are confused and many are angry. It is not uncommon to have calls from people who are desperate for help. They have been shunned by their communities and are trying to hide. NAAF provides information and referrals.

After the initial shock, of finding that their child has alopecia most parents usually start trying to find someone with the miracle cure. They are looking for the injection, the medicine, and the treatment that will restore their child to normalcy and stop the ridicule that they face. Unfortunately it doesn't exist. What we find is that the individual who has alopecia must learn to adapt to a very strange problem. They look different. For some people they are able to cope and grow. Unfortunately, the pain that is cause by the hair loss is the type of pain that is caused by how others react. This reaction is often times that people try to ignore them, and for children it can be that they will be teased, or in some schools that they are even isolated and/or put into a special education classroom. It is a psychological pain that can impact the development of a child's sense of who they are.

Adults too suffer when they have this disease. Frequently people with alopecia believe that they are vulnerable to the stares and grimaces of those around them. People have lost their jobs. A noted news anchor lost his on-air job because he was suddenly perceived as being unappealing. This lack of being appealing (either real or perceived) causes many people to lose confidence in themselves and they begin to withdraw from society.

Recently, one parent called our national headquarters concerning her daughter who has alopecia areata and she was asking for help to stop the harassment that the daughter was experiencing at school. Another parent called who has alopecia areata and had just discovered that her daughter is developing it too. As this parent talked more about her child, she expressed the fears of many parents who have alopecia areata, they don't' want their children to suffer from the turmoil and fears that they had to endure. Both parents wanted to know what they should do or even could do.

Fortunately, there are people who can help, and in many of our support groups people learn how they can help themselves both cosmetically and psychologically. They learn that they are not alone and that they can do something about their sense of vulnerability and isolation. But the real solution will be when we find a cure for alopecia areata.

Our testimony is focused on medical research and the support that is needed to find the cause and cure of alopecia areata. Last year the foundation testified about the upcoming international research symposia. This year we can report that it has taken place. The reports that were presented were significantly different from a similar symposia held several years ago. Information on genetic functions, animal models and others point to a new level of research. We are now ready for a significant research program funded from NIAMS. As the largest private donor agency for alopecia areata, we have been funding research programs to build the base so that a larger and longer-term research program could be developed and funded. Now we think that the research community has developed the ability to spend the public's money well and effectively.

We got to this stage by working as a partner with the National Institute for Arthritis, and Musculoskeletal and Skin Diseases (NIAMS). Our first level of work has been to develop the knowledge base and we have done this conference through the Third International Forum on Alopecia Areata, where NIAMS and NAAF co-sponsored the program and the dissemination of the results. As a result of this meeting we have a much clearer understanding of the disease, how it functions, and possible areas of research that could lead to a cure.

We are very excited about what has been learned. We are looking to you to provide the resources to NIAMS to make this research possible. We like the others in the Coalition of Patient Advocates for Skin Disease Research believe that NIAMS needs more resources. The Coalition, which operates as a voluntary organization and as such, receives no public or private money provides an umbrella to over 21 "lay" skin groups. We suggest that you consider a 15 percent increase in the funding to NIAMS to bring its funding level up to $354 million. This would provide the institute with the ability to implement the results of the recent symposia on alopecia areata and other areas of need. It is also important to note that any research break through in any of the skin areas will likely have a positive impact on the research being done in other areas. We hope that you will consider this request.

The foundation looks forward to continuing to work with the committee as you draft the fiscal year 2000 appropriations bill.

PREPARED STATEMENT OF WILLIAM R. BRINKLEY, PH.D., PRESIDENT, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY

Mr. Chairman, Mr. Harkin, Members of the Subcommittee: I am Dr. William Brinkley, Vice President for Graduate Sciences and Dean of the Graduate School of Biomedical Sciences at Baylor College of Medicine in Houston, Texas. I am a cell biologist who conducts research on cell division and genomic instability in tumor cells. I serve this year as the President of the Federation of American Societies for Experimental Biology, FASEB, the largest organization of life scientists in the United States. Founded in 1912, FASEB is comprised of 17 societies with a combined membership of more than 56,000 researchers.

It is in my role as FASEB president that I appear before you today to ask that you and the other members of this subcommittee continue your leadership and support of the NIH doubling effort begun last year. The potential of science to address the challenges of disease, death and premature disability has never been greater and we ask specifically that you work with your colleagues in the Senate to find the $2 billion increase to fund year II of this effort. FASEB continues to believe that this investment is fully justified, that it can be responsibly managed and that it represents the best hope for reducing the disease burdens which still plague so many Americans and their families.

Mr. Chairman, a half-century of sustained public investment in the National Institutes of Health has given the United States the world's preeminent medical research enterprise. Through a system of competitively awarded grants and in-house research, NIH has fostered the development of a biomedical research initiative that is the envy of the world. Seventy-five of the 118 Nobel laureates in physiology or medicine awarded since 1945 have been Americans. More than two-thirds of these scientists have had their research supported by NIH.

Scientific investigation supported by NIH has given rise to the biotechnology industry and has fueled the development of new therapeutics by the pharmaceutical industry. More importantly, our investment in biomedical research has rewarded the nation with discoveries that have improved health and reduced human suffering from diseases. Let me cite just four recent examples of the critical results derived from prior investment in the NIH:

—NIH-funded researchers have uncovered a mechanism by which common influenza (flu) viruses turn deadly. Normally, influenza A viruses remain confined to the respiratory tract because they need a special enzyme to attack body cells. This enzyme, called protease, is found only in respiratory tract cells. Investigators found, however, that some influenza A viruses can enter cells by using a different enzyme (plasmin), which is more common in human cells. This finding should make it easier to predict the potential for a newly emerging influenza A virus to cause a pandemic. In addition, it suggests new ways of heading off such outbreaks.

— Scientists supported by the NIH have sequenced the complete genome of Treponema pallidum, the bacterium that causes syphilis. The new genetic map should make it easier for scientists to fill the gaps remaining in our ability to detect, treat, and prevent the disease.

—NIH-funded researchers using "knockout" mice that lack the genes for transporting dopamine or serotonin (chemicals by which the brain's cells communicate with each other) found that cocaine's effect on the brain does not depend on either of these neurotransmitters. This finding implies that there are additional target sites in the brain for developing successful therapies for cocaine addiction.

—The Food and Drug Administration has given its approval for the manufacture of a new and safer diptheria-tetanus-acellular pertussis vaccine. The enhanced safety levels derive from the fact that the vaccine uses only a single pertussis antigen and immunization can be achieved with fewer side effects than was possible with older, multi-antigen immunizations.

These are just a few examples of what previous investment has produced. The future looks even brighter. As the U.S. continues to expand its investment in biomedical research, the practice of medicine during the next two decades will change dramatically. Rooted in a deep understanding of how genes guide normal and abnormal molecular function, physicians will use new biomedical and informatics technologies to detect more precisely the risk and presence of disease in order to determine the most effective therapy for each individual patient.

—To meet these emerging opportunities and needs in biomedical research, FASEB recommends $17.9 billion for the NIH, an additional $2.3 billion, a 15 percent increase, over the 1999 appropriation level.

POLICY RECOMMENDATIONS

In addition to its efforts in support of more funding for biomedical research, FASEB and its member societies have an abiding interest in the future directions of medical research, in the decisions about how increased investment should be structured. In March of 1998, a group of working scientists representing FASEB's member societies met to examine the long-term needs for investment in life sciences research. Their report, Molecular Medicine 2020: A Vision for the Future of Medical Research and Human Health, provides a consensus view of the steps that we believe must be taken to capitalize on today's research opportunities and to transform medicine.

As part of its continuing effort to reach the goals and objectives of Molecular Medicine 2020, FASEB presents the following recommendations for NIH in fiscal year 2000.

Priority setting

While the system of merit review and prioritization has proven highly successful, science is inherently dynamic. We applaud the spirit with which NIH has been examining, testing, and improving its system for reviewing grant applications.

Although merit review alone can guide decisions about which projects are most promising within a given field of study, at any moment different fields of biomedical research vary in the opportunities they present for achieving significant advances. Just as decisions about which grants to fund within an area of inquiry depend on the prospects for achieving advances in the near term, decisions about how to allocate funds across fields of inquiry should reflect the opportunities and needs for improving health.

FASEB believes that in prioritizing the allocations of scarce funding policy-makers and science managers should consider the burdens imposed by various human diseases. We welcome the efforts of NIH to receive input from relevant patient communities through mechanisms such as the new Council of Public Representatives recently created by the NIH in response to recommendations of the Institute of Medicine. The practice of medical research, like the practice of medicine itself, is a partnership. Human health will be advanced most effectively when patients, health care providers, medical researchers, and the public have opportunities for input into research priorities.

—FASEB continues to support the NIH system of competitive merit review and the ongoing efforts by NIH to maintain the vibrancy and relevance of this process to newly developing questions and opportunities.

—FASEB supports the continued reliance on scientific opportunity as the principal determinant of NIH research and training programs.

—FASEB also supports efforts of the NIH priority-setting process that includes consideration of disease burden and the inclusion of input from a broad spectrum of constituencies, including the general public and relevant patient, scientific, and medical communities.

Planning

During the past year, while a bipartisan majority of the Congress have supported a multiple year buildup of this country's life science research enterprise, some observers have expressed skepticism as to whether the science enterprise can effectively absorb such a large infusion of resources in a five-year period. FASEB does not share this skepticism and believes the national biomedical research enterprise can effectively use the resources envisioned by Congressional leaders who support a doubling of the NIH budget over five years.

NIH has already begun a planning process that will ensure that new public resources are used effectively and wisely. We believe that these efforts should be expanded. Initially, NIH central leadership deferred to the institutes for planning efforts, but the agency is now deliberately moving to develop NIH-wide plans where appropriate. While avoiding micromanagement and top-down planning, FASEB believes that NIH leadership should continue to identify crosscutting problems, develop strategies for dealing with these issues, and communicate these plans to the Congress and the public. In addition we have made the following recommendation related to NIH planning:

—FASEB encourages NIH to more effectively communicate its planning activities to Congress, the media, and the public.

—FASEB supports the approach of decentralized management of science.

—FASEB encourages NIH to move forward with its planning efforts that relate to crosscutting issues. Specifically, NIH should address matters that are interdisciplinary and inter-institute in nature, and that span the extramural and intramural programs of the agency. Examples include training, infrastructure, and the adequacy of current funding mechanisms.
—In carrying out its planning activities, FASEB recommends that NIH involve both the basic and clinical science communities in identifying issues and developing solutions.

Patient-oriented research

Patient-oriented research is a crucial stage in the translation of basic research findings into improved health care for America's citizens. These studies are essential for translating the findings of basic research into effective therapies, diagnostics, and prevention strategies. Similarly, new knowledge provides a means of strengthening population-based health, especially in the areas of epidemiology and health services.

But, patient-oriented research is now at a critical juncture. It has historically been supported by resources derived indirectly from clinical practice. With increased pressure to contain costs from managed care and other providers, however, this source of funding has largely disappeared. As a result of this change and competing demands, physicians cannot devote the same amount of time and attention to patient-oriented research, which can no longer be maintained at levels where it can fully and effectively exploit all of the emerging opportunities.

—FASEB recommends increased support for high-quality, hypothesis-driven, patient-oriented research through conventional R01 and other investigator-initiated awards, and urges the appropriate involvement of physician-scientists in the review and selection process.
—FASEB also recommends increased funding for the infrastructure of patient-oriented research programs and centers.

Physician-scientists

Physician-scientists play a unique role in biomedicine by studying patients and their diseases. They take their observations from the bedside into the laboratory, make basic discoveries, and translate these discoveries into new methods for prevention, diagnosis, and treatment of disease. This combination of clinical and scientific skills is essential for improving the understanding and treatment of human disease.

But factors constraining patient-oriented research have also had a profoundly negative impact on the ranks of physician-scientists. The next generation of clinically trained researchers is at risk without support for training and career development. If this is allowed to occur, we will have a drastically reduced capacity for translational research, loss of a critical source of research insights, and diminished ability to train future generations of medical students in the context of scientific method.

—FASEB believes that training research-oriented physicians is critical to the future of biomedicine.
—FASEB recommends that the support of research training for physician-scientists adequately cover salaries of trainees, training costs to mentors, and institutional indirect (facilities and administrative) costs.
—FASEB recommends increased support for programs that specifically promote rigorous training opportunities for medical students with an interest in research.
—FASEB also recommends increased funding of training grants and individual NRSAs for two years of research training for physicians. This funding should also cover graduate course work when appropriate. Physicians engaged in such training should receive a stipend equivalent to that for clinical training; other support should be similar to that provided to Ph.D. postdoctoral trainees.
—FASEB supports implementation of mechanisms to remove disincentives to the career development and retention of physician-scientists. These include debt forgiveness for medical education costs, and the elimination of salary caps that keep extramural physician salaries below the salary scales for comparable physician-scientists in the NIH intramural program.

New technologies for research: advanced technology, instrumentation, and national research resources

The $67 million spent annually by the federal government to run these centers has not relieved concerns regarding the chronic underfunding of these resources. They are critical to maintaining the forefront in existing key research technologies that R01 investigators have come to rely on. Additional resources would increase opportunities for investigators to use shared technological resources including the de-

velopment of "collaboratories" or "laboratories without walls," which would enable the remote access of the resource centers via the Internet or by encouraging natural interconnectivity of research resources with clusters of P01s focused on particular large-scale problems.

The National Center for Research Resources/Biomedical Technology program provides three mechanisms for support in this arena: R01, P41, and S10 grants. Each program plays a unique role in the development and acquisition of technology. R01s are needed to conceptualize and innovate; P41s are necessary to develop cutting-edge, expensive, and scarce technology, make it work, and make it available to the research community. The S10 program permits groups of researchers to share in expensive, commercially available, off-the-shelf instruments.

—FASEB recommends that funding for the shared biomedical technology resource program (P41) be increased from its current level of $67 million to $167 million.

—FASEB recommends increasing the funding for support of shared instrumentation to $80 million.

—FASEB recommends a new expenditure by NIH of at least $250 million annually for the sustained development of the next generation DNA sequencing technologies and of breakthrough technologies for elucidating the biological function of proteins. The system of shared technology centers funded at 64 cities around the United States is a critical resource for taking advantage of the knowledge emerging from research on the human genome.

—FASEB recommends that NIH expand its commitment to foster and support technological developments.

The burden of federal regulations

Excessive federal regulations consume valuable resources and divert researchers' energies from their work. Some of these regulations were originally designed for purposes unrelated to research, and their application to academic laboratories has had unanticipated and costly consequences for scientists. Ultimately, such regulations undermine the scientific progress which, in many cases, is being funded by the federal government.

—FASEB supports NIH's ongoing study of ways to reduce the unnecessary burden that federal regulations impose on researchers. We hope that the recommendations of the study receive widespread consideration.

CONCLUSION

Other recommendations that FASEB believes will maximize the public's return on investment from NIH funding are included in the formal report of our fiscal year 2000 Funding Consensus Conference, which has been sent to all members. We hope you will have time to review the full report.

In conclusion, Mr. Chairman, I want to restate that while each sector of the research establishment brings its own different perspective to this debate, all are here with one overarching goal—progress against the diseases and disabilities that continue to afflict the American people and the people of the world. While FASEB's members are practitioners of molecular biology, biochemistry, anatomy, and other basic sciences, their cause is to apply their science to the reduction of human suffering caused by disease. As I consider others submitting statements for the record to this Subcommittee, families fighting Sudden Infant Death Syndrome, juvenile diabetes, breast cancer, AIDS or Muscular Dystrophy, I know that these groups represent the causes that the biomedical science community is committed to.

The basic message of these patient advocates and the scientists whom I represent is the same. Investment in biomedical research is the first and critical step in prevention, treatment and control of disease, which, in turn, will lead to longer, healthier and more active lives. Without adequate funding of the NIH progress will be slowed and suffering will be prolonged.

As this Subcommittee reviews our request for a 15 percent increase in funding for next year, we believe you should do so in the context of the remarkable accomplishments that past investments in the NIH have produced.

PREPARED STATEMENT OF ONE VOICE/THE AMERICAN COALITION FOR ABUSE AWARENESS

ISSUE

Whether the National Institutes of Health are justified in proposing fiscal and developmental cutbacks in research programs and empirical initiatives focusing on

child sexual abuse and later physiological, neurobiological and psychological consequences for adult survivors.

CONCLUSION

This is not an area which can afford less attention or resource allocation. Here, at issue is the health and welfare of children and adults, and the significant negative impact that instances and patterns of sexual abuse have on their lives. The Child Abuse Prevention and Treatment Act became law in 1974, and "[s]ince that time, the Federal government has served as a catalyst to mobilize society's social service, mental health, medical, educational, legal, and law enforcement resources to address the challenges in the prevention and treatment of child abuse." [1] The numerous federally sponsored child welfare programs underscore Congress' recognition of the need to protect the nearly 70 million children under the age of eighteen in this country.[2] Of the one million children determined to be victims of abuse or neglect in 1996, approximately 120,000 were sexually abused.[3]

Acts of sexual abuse and assault have reached frightening numbers: [4] current authorities estimate that one in every three girls and one in four boys will be victims of unwanted sexual touch or abuse before the age of eighteen.[5] Despite our cognizance of this injustice, there persists an outrageous number of substantiated child sexual abuse cases in the United States: in 1996 alone, this number was 119,397.[6] These numbers, however, reflect only those cases reported; not all children report abuse,[7] and, tragically, are deprived of safety and well-being.

We know that child sexual abuse exacts an enormous toll on the cognitive and emotional development of the child. Studies show that child sexual abuse is consistently coupled with difficulties in school, in relating to peers, and in sleeping; in later childhood, these afflictions can evolve into eating disturbances, such as bulimia and anorexia nervosa, social regression, and self-destructive or suicidal behavior.[8] In addition, seventy to eighty percent of sexual abuse survivors report excessive use of drugs or alcohol; women who reported childhood rape were three times more likely to become pregnant before the age of eighteen.[9]

Daily, more is being learned of the physiological consequences of child sexual abuse. Doctors and researchers at esteemed medical institutions such as Harvard and Yale universities have observed a strong correlation between child sexual abuse and a disruption to the normative function of stress and sex hormones in the body.[10] Sexual abuse survivors have been found to have a significantly diminished long-term capacity for short-term memory,[11] an increased vulnerability to temporal lobe

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[1] Kathleen Coulborn-Faller, U.S. Dep't of Health and Human Servs., Child Sexual Abuse: Intervention and Treatment Issues vii (1993).

[2] U.S. Dep't of Com. Bureau of the Census, PPL–57 Resident Population Estimates by Age, Sex, and Race, Mar. 1, 1997 (hereinafter "Census").

[3] U.S. Dep't of Health and Human Servs., Child Maltreatment 1996: Reports From the States to the National Child Abuse and Neglect Data System xi (1996) (hereinafter "Child Maltreatment 1996") (based on reports received and referred for investigation by Child Protective Services in 1996).

[4] Center for the Future of Children, Sexual Abuse of Children, 4 The Future of Children 2 (Summer/Fall 1994).

[5] Coulborn-Faller, supra note 1, at 16–17.

[6] Child Maltreatment 1996, supra note 3, at 2–7.

[7] The National Victim Center Handbook, 1991, reported that 90 to 95 percent of all sexual abuse cases go unreported to the police. See also Coulborn-Faller, supra note 1, at 16–17. The National Committee to Prevent Child Abuse reports that, in 1997, there were 223,650 reports of child sexual abuse.

[8] Coulborn-Faller, supra note 1, at 27–28.

[9] Center Against Sexual Abuse Statistical Report 1997 (hereinafter "CASA").

[10] J. Douglas Bremner, et al., Magnetic Resonance Imaging-Based Measurement of Hippocampal Volume in Posttraumatic Stress Disorder Related to Childhood Physical and Sexual Abuse—a Preliminary Report, 41 Biol. Psychiatry 23–32 (1997).

[11] Id. at 26 (reporting a 12 percent deficit in hippocampal volume in adult survivors of child sexual abuse).

epilepsy,[12] and weakened immune system function,[13] among other disorders;[14] recently, Discover magazine published a report supporting these findings.[15] The long-term ramifications of these conditions impact heavily on how child sexual abuse should be perceived.

BACKGROUND AND INTEREST OF ONE VOICE/THE AMERICAN COALITION FOR ABUSE AWARENESS

We are disconcerted by and have evidence of NIH/NIMH's apparent lack of sensitivity towards the issue of child sexual abuse. In August of 1998, NIH/NIMH presented "The Three Faces of Eve," in conjunction with the Science and Film Festival. To facilitate discussion on the issue of Dissociative Identity Disorder ("DID"), Festival directors went outside the Institutes and invited Dr. Paul McHugh. DID condition has been closely associated to early sexual abuse.[16] It is our contention, and indeed, our concern, that Dr. McHugh's documented agenda against further exploration into and study of DID stems from a disavowal of the trauma experienced by sexual abuse survivors, and a complete reluctance to believe current scientific evidence of the prolonged sequelae of child sexual abuse. The close association between child sexual abuse and DID justifies the interpretation of this reluctance as a concomitant hesitancy to believe current data of the pervasive nature of child sexual abuse itself.

More alarming than Dr. McHugh's position was that of the Institutes. In response to the invitation of Dr. McHugh, One Voice/ACAA initiated a letter writing campaign to involve the medical and scientific communities in raising the awareness of the Institutes with regard to DID and other mental health concerns of those suffering the after-effects of long-sustained childhood abuse. Several nationally recognized organizations, including the International Society for the Study of Dissociation and Yale University School of Medicine's Departments of Diagnostic Radiology and Psychiatry, joined us in writing to protest the actions taking by the Institutes.

The choice to present Dr. McHugh indicates a move by Institute officials to reduce the attention paid to child sexual abuse as a public health issue. This is further evidenced by the 1999 dissolution of the NIH/NIMH's Developmental Traumatology Unit. Instrumental in our understanding of the science of trauma, this center has been at the forefront of tracing the developmental effects of child sexual abuse for years. Yet, this year, the Institutes terminated the Unit. Again we find ourselves in disagreement with the policy perspective the Institutes have chosen to adopt. Many of the same individuals who supported our effort his summer now support our position that any reduction by the Institutes in funding directed toward child sexual abuse is in opposition to current medical findings that adverse childhood experiences have a substantial and significant impact on the health of American society.

A DEFINITION OF CHILD SEXUAL ABUSE

Despite consistent findings that between eleven percent and sixty-two percent of women,[17] and between three percent and thirty-nine percent of men [18] endure some form of child sexual abuse, and despite the formal recognition of its negative impact

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[12] Shannon Brownlee, The Biology of Soul Murder, U.S. Online News (Nov. 11, 1996) <http://www/usnews.com/usnews/issue/11trau.htm> (citing the findings of Martin H. Teicher, Ph.D., M.D., of tiny seizures occurring in various sectors of the brain in adult survivors of child sexual abuse).

[13] Tori DeAngelis, New Threat Associated With Child Abuse, APA Monitor (Apr. 1995) (citing Frank Putnam, Jr., of the National Institute of Health's Laboratory of Clinical Psychology, who has evidenced high levels of antibody associated with weakened immune system function in adult survivors of child sexual abuse).

[14] See, e.g., Minouche Kandel & Eric Kandel, Biology of Recovered Memory, Discover Magazine 32 (May 1994); Elliot Stellar & Bruce McEwen, Stress in the Individual, 153 Arch. Intern. Med. 2093–101 (Sept. 27, 1993).

[15] Robert Sapolsky, Stress and Your Shrinking Brain, Discover Magazine 116 (Mar. 1999).

[16] Etzel Carde—a, Dissociation Disorders, in Adult Psychopathology and Diagnosis 384–408 (Samuel M. Turner & Michel Herson eds., 3d ed. 1997); Philip M. Coons, Confirmation of Childhood Abuse in Child and Adolescent Cases of Multiple Personality and Dissociative Disorder Not Otherwise Specified 182 J. Nervous & Mental Disease 461–64 (1994).

[17] Diana E.H. Russell, The Incidence and Prevalence of Intrafamilial and Extrafamilial Sexual Abuse of Female Children, 7 Child Abuse & Negl. 133–46 (1983). See also D. Finkelhor & G. Hotaling, Sexual Abuse in the National Incidence Study of Child Abuse and Neglect, 8 Child Abuse & Negl. 22–32 (1984).

[18] Finkelhor & Hotaling, supra note 17. See also G. Kercher & M. McShane, The Prevalence of Child Sexual Abuse Victimization in an Adult Sample of Texas Residents, 8 Child Abuse & Negl. 495–502 (1984).

on society,[19] child sexual abuse remains an issue seldom discussed and seldom clarified. The term "child sexual abuse" covers a wide range of acts. It encompasses "any sexualized behavior that harms or traumatizes a child," [20] and especially "the exploitation of a child for a sexual purpose by another person." [21] Experts have come to recognize that child sexual abuse may be "overt or covert," where

> [o]vert sexual abuse includes any inappropriate touching of a child's genitals or breasts and intercourse or penetration—or touching—with adult genitals, finger or fingers, or another object. In covert sexual abuse there is often a lack of physical contact . . . . It may include:telling a child dirty jokes, inappropriate nudity, preoccupation with a child's genitals or with one's own genitals with the child, preoccupation with a child or adolescent's sexuality, telling a child or adolescent of one's own sexual escapades, any preoccupation with talking about sexual behaviors or showing a child explicit sexual pictures, flirting with the child, and the like. Covert sexual abuse nearly always accompanies the overt.[22]

Thus, children who are being or who have been sexually abused experience a wide range of reactions to the abuse. These will be outlined in the next two sections.

PUBLIC HEALTH CONCERNS: SOCIAL RAMIFICATIONS OF CHILD SEXUAL ABUSE IN CHILDREN AND ADULTS

Major indicators of child sexual abuse are observed in almost all facets of a child's life.[23] In school, teachers may notice a child's inattention, disruptive behavior, or other changes in demeanor that often result in falling grades.[24] Parents may notice a loss of appetite, evidence of eating disorders,[25] increased nightmares, depression,[26] anxiety,[27] or other nonsexual behavioral changes.[28] Frequently, children being abused will polarize, either acting out at others, or withdrawing into themselves.[29] In the instance when the child acts out at another, that acted upon child may then be subject to similar feelings; sadly, his subsequent insecurity and depression are the direct result of the abused child's own insecurity and depression.[30] In 1993, the American Psychiatric Association stated that "abuse tends to produce an inappropriate conditioning of sexual responsiveness, the shattering of a child's trust and an enduring sense of stigmatization and powerlessness." [31]

The APA also found subsequent symptoms in adult survivors of child sexual abuse, as have other studies:

> [F]rom a detailed analysis of 38 clinical studies (on 2,774 child sexual abuse survivors compared to 8,388 controls who were not sexually abused) meeting rigorous research criteria, Neumann and colleagues [32] found that there was a significant association between a sexual abuse history and

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[19] Bremner, supra note 10, at 23 (citing D. Finkelhor, A Sourcebook on Childhood Sexual Abuse (1986) (finding that rates of child sexual abuse are currently estimated at 11–62 percent in women, and 3–39 percent in men)). See also Child Maltreatment 1996, supra note 3.

[20] Charles L. Whitfield, M.D. Traumatic Amnesia: The Evolution of Our Understanding From a Clinical and Legal Perspective, 4 Sexual Addiction & Compulsivity 7 (1997).

[21] Carole S. Miller, When You Tell, Does the Hurt Go Away?: The Impact of Theatre & Education in Sexual Abuse Prevention, 8 Stage of the Art: J. Am. Alliance for Theatre & Educ. 13 (Summer 1996).

[22] Whitfield, supra note 20, at 7 (citing C.A. Courtois, Healing the Incest Wound: Adult Survivors in Therapy (1989); J.N. Briere, Child Abuse Trauma: Theory and Treatment of the Lasting Affects (1992)).

[23] Videotape: Once Can Hurt a Lifetime (Marilyn Van Derbur for One Voice, 1994).

[24] S.D. Peters et al., Prevalence, in A Sourcebook on Child Sexual Abuse 15–59 (D. Finkelhor, ed., 1986).

[25] J. Douglas Bremner et al., Deficits in Short-Term Memory in Adult Survivors of Childhood Abuse, 59 Psychiatry Res. 97, 98 (1995) (citing R.C. Hall et al., Sexual Abuse in Patients With Anorexia Nervosa and Bulimia, 30 Psychosomatics 73–79 (1989); R.L. Palmer et al., Childhood Sexual Experiences With Adults Reported by Women With Eating Disorders: An Extended Series, 156 Brit. J. Psychiatry 699–703 (1990)).

[26] Bremner, supra note 25, at 98 (citing J. Briere, et al., Symptomatology in Men Who Were Molested As Children: A Comparison Study, 58 Am. J. Orthopsychiatry 457–61 (1988); C. Swett, Jr., et al., Sexual and Physical Abuse Histories and Psychiatric Symptoms Among Male Psychiatric Patients, 147 Am. J. Psychiatry 632–36 (1990)).

[27] Id.

[28] National Ctr. on Child Abuse and Neglect, U.S. Dep't of Health and Human Services, Child Sexual Abuse: Intervention and Treatment Issues (1993).

[29] Van Derbur, supra note 23.

[30] Id.

[31] American Psychiatric Ass'n, Diagnostic and Statistical Manual of Mental Disorders (4th ed. 1994).

[32] D.A. Neumann et al., The Long-Term Sequelae of Childhood Sexual Abuse in Women: A Meta-Analytic Review, 1 Child Maltreatment 6–16 (1996).

adult symptoms. These symptoms included: anxiety, anger, depression, re-victimization, self-mutilation, sexual problems, substance abuse, suicidality, low self-esteem, interpersonal problems, obsessions and compulsions, dissociation, post-traumatic stress responses, and somatization (physical problems).[33]

One such study, conducted by the Centers for Disease Control's National Center for Chronic Disease Prevention and Health Promotion, is known as the "Adverse Childhood Experiences (ACE) Study."[34] Using over nine thousand subjects in conjunction with Kaiser Permanente's San Diego Health Appraisal Clinic, the study linked childhood abuse to a four to twelve-fold increase of health risk for alcoholism, drug abuse, depression, and suicide attempt; a two to four-fold increase in smoking, poor self-rated health, sexual partners numbering more than or equal to 50, and sexually transmitted disease; and a 1.4 to 1.6-fold increase in physical inactivity and severe obesity. The study also found adverse childhood experiences in graded relationship to the presence of adult diseases including ischemic heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease.[35] These findings command notice.

The American Psychiatric Association has also concluded that victims of child sexual abuse are "more prone to depression, substance abuse, sexual problems and thoughts of suicide."[36] Interestingly, these are symptoms commonly associated with Posttraumatic Stress Disorder ("PTSD").[37]

The experience of traumatic stress,[38] which has an impact similar to repeated stress, differs from the normal stresses that we experience in our daily lives (for example, when a tire goes flat, a wallet is lost, or a job is lost).[39] It occurs when a person is seriously harmed physically or psychologically and especially where there is no supportive human environment in which to process the experience and heal. Its effects are usually more severe when the trauma is of human origin, and is even more severe when it comes from primary caregivers, such as parents or parent figures. The specific trauma of child sexual abuse is harmful in most of these regards.[40]

As a child endures the trauma associated with child sexual abuse, and especially where the abuse is at the hands of someone the child loves or trusts, he or she is forced to accept the experience, through repression, dissociation,[41] or other behav-

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[33] Whitfield, supra note 20, at 2.

[34] Vincent J. Felitti et al., Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults: The Adverse Childhood Experiences (ACE) Study, 14 Am. J. Prev. Med. 245 (1998).

[35] Id.

[36] American Psychiatric Ass'n, supra note 31. See also G.B. Ladwig & M.D. Anderson, Substance Abuse in Women: Relationship Between Chemical Dependency in Women and Past Reports of Physical and Sexual Abuse, 24 Int'l J. Addict 739–54 (1989); G.R. Brown & B. Anderson, Psychiatric Morbidity in Adult Inpatients with Childhood Histories of Sexual and Physical Abuse, 148 Am. J. Psychiatry 55–61 (1991).

[37] Whitfield, supra note 20, at 2.

[38] Traumatic stress has been most thoroughly documented with respect to combat veterans. J. Douglas Bremner et al., Childhood Physical Abuse and Combat-Related Posttraumatic Stress Disorder in Vietnam Veterans, 150:2 Am. J. Psychiatry 235 (Feb. 1993). Recently, the analogy has been extended to and researched with regard to child sexual abuse survivors, with intriguing results:

"Individuals abused in childhood may have acquired characteristic methods of coping with stressful experiences, such as emotional numbing, which may, in fact, make them more susceptible to subsequent trauma such as combat stress . . . . In other words, exposure to stress early in life increases the vulnerability to psychopathology in response to subsequent stressors . . . ."—Id. at 238.

[39] See generally Whitfield, supra note 20, at 1; Sapolsky, supra note 15.

[40] Whitfield, supra note 20.

[41] See Judith L. Herman, Crime and Memory, 23 Bulletin of the American Academy of Psychiatry and the Law 5–17 (1995) ("Peripheral detail, context, and time sense fall away, while attention is strongly focused on central detail in the immediate present. When the focus of attention is extremely narrow, people may experience profound perceptual distortions, including insensitivity to pain, depersonalization, time slowing and amnesia. This is that state we call dissociation . . . .").

ior.[42] This implicit acceptance is often termed "child sexual abuse accommodation syndrome,"[43] which commonly results in PTSD.[44]

Moreover, as previously mentioned, the symptoms usually descriptive of PTSD are predominantly those which are central to the experience of child sexual abuse survivors.[45] Also related are

> a wide array of psychiatric and psychological problems associated with the PTSD occurring in these people. These problems include: depression, increased fears, sexual problems, feelings of isolation, guilt, distrust, anger, low self-esteem, self-destructive behaviors, nightmares, sleep difficulties, phobias, substance abuse, a tendency to reenact the trauma and to be revictimized, and aggressive behavior. These psychiatric and psychological symptoms appear in most cases to be the after-effects of the trauma, and do not reflect defects of character or personality of the victims.[46]

The National Institute of Justice reports that "[p]eople who were sexually victimized during childhood are at higher risk of arrest for committing crimes as adults, including sex crimes, than are people who did not suffer sexual or physical abuse or neglect during childhood."[47] "Among children who were sexually abused, the odds are 27.7 times higher than for the control group of being arrested for prostitution as an adult."[48] A report issued by the Department of Justice indicates that, of the more than 40,000 women currently imprisoned in state systems nationally, 34 percent reported being sexually abused as children.[49] This number represented over three-quarters (78.8 percent) of the female prisoners who had reported abuse (physical or sexual).[50]

There is clear evidence that the psychological consequences of child sexual abuse are having profound effects on the well-being of our society.[51]

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[42] Jennifer J. Freyd, Betrayal Trauma: The Logic of Forgetting Childhood Abuse 75 (1996) ("the trauma of child abuse, by its very nature, requires that information about the abuse be blocked from mental mechanisms that control attachment and attachment behavior.").

Marilyn Van Derbur, former Miss America, describes the necessity of repressing the experience of child sexual abuse as follows:

"I would disclose my secret to one person at a time, knowing that the person I told, each and every time, would . . . finally know how dirty, bad, ugly, unlovable, and unacceptable I was. How could a former Miss America be an incest survivor? How could a father pry a little girl open, starting at age five, and continue until she left for college at age eighteen? How could I possibly repress those experiences? The more relevant question would be, how could I not? How could any child lie in bed, night after night, year after year, wondering if tonight would be the night. That kind of terror, that kind of horror could not be endured or contained for any long period of time. Splitting my mind was a miraculous survival tool. How I bless my child/mind for finding a way to survive."

Marilyn Van Derbur, Foreword, in Long and Mature Considerations: A Legal Guide for Adult Survivors of Child Sexual Abuse iii (1997).

[43] Whitfield, supra note 20, at 1 (citing J. Davidson, Issues in the Diagnosis of Post-traumatic Stress Disorder, in PTSD: A Clinical Review (R.S. Pynoos, ed., 1993) and R. Summit, The Child Sexual Abuse Accommodation Syndrome, 7 Child Abuse & Neglect 177–93 (1983)).

[44] Id.

[45] Whitfield, supra note 20, at 2 (citing A.B. Rowan & D.W. Foy, PTSD in Child Sexual Abuse Survivors: A Literature Review, 6(1) J. Traumatic Stress 3, 3–20 (1993)).

[46] Id.

[47] Cathy Spatz Widom, National Institute of Justice, Victims of Childhood Sexual Abuse: Later Criminal Consequences (Mar. 1995).

[48] Id. See also Statement of Christine Glazier (July 2, 1998), finding that: "one consequence of childhood abuse is not knowing what 'normal' relationships are and [having] no sense of what 'inappropriate' meant in terms of how I was treated by people. A child can only know what they learn and the associations that one makes in childhood [are] without benefit of maturity, education or reasoning . . . I, in my confusion about what was 'good' in a woman, would actually find myself in continued situations where I was the 'victim' of . . . a total misreading of the actual intentions of most of the men in my life. I truly believed that all men really wanted was a sexual relationship. That nothing else mattered and that if I did not have sex I would be punished. Even more important, I felt like a failure . . . . Many times I just wanted someone to hold me. And the way I got someone to hold me as a child was to perform."—Id.

[49] Tracy Snell, U.S. Dep't of Justice, Survey of State Prison Inmates (1991).

[50] Id.

[51] Whitfield, supra note 20, at 2 (citing A.B. Rowan & D.W. Foy, PTSD in Child Sexual Abuse Survivors: A Literature Review, 6(1) J. Traumatic Stress 3, 3–20 (1993)); Neumann, supra note 32, at 6–16 ("From the finding of these above recent extensive reviews of the clinical research literature, it is clear that child sexual abuse harms most victims in these numerous ways, and that these symptoms are usually the direct result of the sexual abuse itself and are not likely to be due to other causes.").

PUBLIC HEALTH CONCERNS: PHYSIOLOGICAL DETRIMENT IN ADULT SURVIVORS OF CHILD SEXUAL ABUSE

While the effects of child sexual abuse on a child's psychological development are easy to understand, a new area of concern is emerging: it is not only children's emotions that are compromised by sexual abuse, but their physiological functions, as well.[52]

Recent studies exploring the physiological effects of child sexual abuse have found ramifications of abuse to be far more encompassing than might be thought.[53] While it has long been accepted that signals of child sexual abuse can include a loss of appetite, falling grades in school, depression, anxiety or other nonsexual behavioral changes,[54] the idea that sexual abuse may have actual physical consequences (apart from genital afflictions) has only recently been proffered—and proven.[55]

Neurological abnormalities associated with a history of abuse have been found through the use of methods such as neurological examinations, electroencephalograms (EEG) and brain electrical activity mapping, computerized tomography (CAT) scans, and magnetic resonance imaging (MRI), and neuropsychological testing.[56] These procedures yielded evidence of increased electro-physiological abnormalities in subjects with a history of child sexual abuse, as compared to nonabused subjects; abnormalities were concentrated in the left side of the frontal, temporal, or anterior regions.[57]

When research in this area first began, it was suspected that these findings would support the hypothesis that early and sustained sexual abuse causes the development of the brain to be altered, especially development of the brain's limbic structures.[58] This thesis has now been documented, with child sexual abuse occuring before the child was eighteen years of age[59] substantially correlated to a measure[60] of "somatic, sensory, behavioral and memory symptoms suggestive of temporal lobe epilepsy."[61]

According to neuroscientists, traumatic experiences, such as child sexual abuse, alter the "normal" course of physiological response, affecting stress and sex hormones in the body.[62] More specifically, the repetitive stress caused by child sexual abuse effects an imbalance in the body's neurotransmitters: the volume of some, such as norepinephrine and serotonin, is reduced, while other chemicals, such as enkphalins (opiates) and steroids suffer no such depletion.[63] In addition, a correlation between an increased presence of glucocorticoids and a loss of neurons, plus an inactivity of dendric branching in the hippocampus, that part of the brain responsible for storing short-term memories into long-term memories, has been observed.[64] This disregulation causes atrophy of the hippocampal nerve cells: cells begin to weaken and break down, dissolving in size, which disrupts their connections, leading to their death. Consequently, the hippocampal function is significantly impaired.[65] In addition to evidence of hampered left-hemisphere cerebral growth, there is concomitant evidence of early accelerated growth of the right hemisphere, associ-

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[52] Ronald Kotulak, Epidemic of Violence and Stress is Devastating Kids' Brains, Chi. Trib., Apr. 14, 1993, at N1.

[53] Brownlee, supra note 12.

[54] Coulborn-Faller, supra note 1.

[55] Martin Teicher, Increased Prevalence of Electrophysiological Abnormalities in Children With Psychological, Physical, and Sexual Abuse, 5 J. Neuropsychiatry & Clin. Neurosci. 401–08 (1993).

[56] Id.

[57] Id.

[58] Id.

[59] Martin Teicher, Early Childhood Abuse and Limbic System Ratings in Adult Psychiatric Outpatients, 5 J. Neuropsychiatry & Clin. Neurosci. 301–30 (1993).

[60] Arthur J. Vander et al., Human Physiology: The Mechanisms of Body Function 222 (6th ed. 1994) ("The Limbic System is associated with learning, emotional experience and behavior, and a wide variety of endocrine functions . . . the parts of the Limbic System are connected with many other parts of the central nervous system.").

[61] Id.

[62] Kotulak, supra note 52. See generally, R. Joseph, Neuropsychiatry, Neuropsychology, Clinical Neuroscience: Emotion, Evolution, Language, Memory & Abnormal Behavior (2d ed. 1996) (discussing the effects of child sexual abuse induced stress on neurotransmitters and, consequently, the hippocampus and amygdala).

[63] Joseph, supra note 62.

[64] Bremner, supra note 10, at 24 (citing H. Uno et al., Hippocampal Damage Associated with Prolonged and Fatal Stress in Primates, 9 J. Neurosci. 1705–11 (1989)). See also R.M. Sapolsky et al., Hippocampal Damage Associated With Prolonged Glucocorticoid Exposure in Primates, 10 J. Neurosci. 2897–2902 (1990).

[65] Joseph, supra note 62; Telephone interview with Dr. Bruce McEwen, Ph.D., neuroscientist, Rockefeller University.

ated with increased emotions, "particularly negative" ones.[66] Thus, while the hippocampus is injured, the amygdala, responsible for the storage of emotional memories, remains intact, keeping the trauma of child sexual abuse close in the survivor's mind.[67]

Studies focusing solely on the affects of child sexual abuse on the hippocampus have reported a twelve percent depletion in hippocampal volume in survivors of child sexual abuse, as compared with nonabused control subjects matched for variations in age, sex, alcohol and substance use, education and other potentially confounding factors.[68] The studies have found deficits in verbal short-term memory[69] and found that "left hippocampal volume was correlated with duration of childhood abuse (measured in years)."[70] While the hippocampal volume in child sexual abuse survivors was less than that in nonabused controls, child sexual abuse survivors experiencing PTSD had a greater volume of the left temporal lobe than that of their nonabused counterparts.[71] Accordingly, "childhood abuse patients with PTSD perform better than controls on visual memory tasks, although verbal memory is significantly worse."[72]

It is not just that memory is worse as a result of these impairments; "considerable evidence supports a relationship between stress and alterations in memory."[73] Neurotransmitters and neuropeptides, such as those described above, "have the potential to result in an overconsolidation of memory traces," an occurrence which provides an explanation for the intrusive memories frequently experienced by PTSD-affected child sexual abuse survivors.[74] While this paper will not engage in the current discourse on the etiology of dissociative amnesia, should be noted that "[t]he fact that many individuals forget episodes of childhood abuse is well established. As many as 38 percent of trauma victims who experienced abuse severe enough to result in a visit to a hospital emergency room had no memory of the event twenty or more years later."[75]

While a link between child sexual abuse and a deficiency of the immune system can be readily established via the instances of abuse and penetration which lead to the transmission of disease, including Human Immunodeficiency Virus (HIV),[76] another route has now been identified: child sexual abuse, with the stresses it causes, "can impair the brain's physical development and leave victims with permanently weakened immune function."[77] More such studies, pointing to a crucial relationship between the nation's physical well-being and child sexual abuse are emerging, elucidating a pressing need to combat child sexual abuse and the factors that contribute to its occurrence.

Deficits in memory capabilities have ramifications on the possibility of treatment for adult survivors of severe child sexual abuse:[78] as patients with a history of se-

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[66] Marilyn Elias, Sexual Abuse Can Weaken Victims' Immune System, USA Today (quoting Dr. Martin Teicher of Harvard Medical School, who has also studied the effect of sexual abuse on the electrical activity levels of the brain).

[67] Joseph, supra note 62. Impacts of this process include memory loss, amnesia, and PTSD, as well as other emotional and neurological abnormalities. Id. See also R.K. Pitman, Post-Traumatic Stress Disorder, Hormones, and Memory, 26 Biol. Psychiatry 221–23 (Editorial) (1989); J. Douglas Bremner et al., Functional Neuroanatomical Correlates of the Effects of Stress on Memory, 8 J. Traumatic Stress 527–54 (1995).

[68] Bremner, supra note 10, at 26, 29 (citing J. Douglas Bremner et al., Deficits in Short-Term Memory in Adult Survivors of Childhood Abuse, 59 Psychiatry Res. 97–107 (1995)).

[69] Bremner, supra note 25 , at 102 ("Adult survivors of abuse had deficits in verbal short-term recall, as measured by decreased scores on the Logical component of the WMS (Weschler Memory Scale) for immediate recall and delayed recall, but not percent retention. Adult survivors of abuse also had deficits in verbal recall, as measured by the VeSRT (Verbal Selective Reminding Test).").

[70] Bremner, supra note 10, at 24, 29.

[71] Id. at 30.

[72] Id.

[73] Bremner, supra note 25, at 98.

[74] Bremner, supra note 25, at 98 (citing R.K. Pitman, Post-Traumatic Stress Disorder, Hormones and Memory, 26 Biol. Psychiatry 221–23 (Editorial, 1989); R.K. Pitman et al., Effects of Intranasal Vasopressin and Oxytocix on Physiologic Responding During Personal Combat Imagery in Vietnam Veterans with Post-Traumatic Stress Disorder, 48 Psychiatry Res. 107–17 (1993)).

[75] J. Douglas Bremner et al., Neural Mechanisms in Dissociative Amnesia for Childhood Abuse: Relevance to Current Controversy Surrounding the "False Memory Syndrome", 153 Am. J. Psychiatry 7, 71 (July 1996 Festschrift Supplement) (citing L.M. Williams, Recall of Childhood Trauma: A Prospective Study of Women's Memories of Child Sexual Abuse, 62 J. Consult Clinical. Psychol. 1167–76 (1994)).

[76] K. Lanning, U.S. Dep't of Justice, Child Molesters: A Behavioral Analysis for Law Enforcement (1986).

[77] Elias, supra note 67.

[78] Bremner, supra note 25, at 105.

vere child sexual abuse may have consequential learning impairments which impact negatively on their academic success,[79] any rehabilitation program that directs a psychiatric patient (as child sexual abuse survivors often are) back towards the classroom may have an ill-fated chance of benefitting the patient.[80] In the event that the child sexual abuse survivor is able to overcome the persistent psychiatric and psychological afflictions involved, the physiological detriment stemming from a history of child sexual abuse may prove to be too sizable a block to reintegration into society—or at least, the workforce.[81] Practical examples of academic disadvantage, which can be readily connected to child sexual abuse, "underscore the magnitude of childhood abuse as a major public health problem."[82]

CONCLUSION

Child sexual abuse is a silent threat to the health of our society. Its ramifications, as they spread into the social, physical, and psychological aspects of North American society, are as pervasive as they are dangerous. The negative consequences of child sexual abuse often perpetuate the existence of the source they rebel against: many child sexual abuse survivors cyclically act upon their learned experience and abuse others. As the trauma spreads, then, the effects of that trauma erode the health of our social fabric, imposing a vulnerability akin to that of a sickly child.

Just as we pay close attention to the physical ailments that assault us as individuals daily, we must become sedulous to take note of this most violent affliction. Given the substantial base of new knowledge regarding the overall impact of child sexual abuse on the health of society, cutbacks or reappropriation of funding directed to the study of the effects of child sexual abuse is both irresponsible and in conflict with the stated goals of the Institutes. Please consider a budget that reflects a concern for children and adult survivors of child sexual abuse. To do otherwise would be to ignore the daily structural damage committed against children and adult citizens, and to wrongly equate silence with safety.

PREPARED STATEMENT OF CHRISTINE STEVENS, SECRETARY; CATHY LISS, SENIOR RESEARCH ASSOCIATE; AND ADAM ROBERTS, RESEARCH ASSOCIATE, SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

$8.6 MILLION IS NEEDED FOR THE RETIREMENT AND CARE OF FORMER RESEARCH CHIMPANZEES

The Society for Animal Protective Legislation respectfully requests an appropriation of $8,547,600 for the immediate, permanent retirement and humane care of chimpanzees no longer needed in biomedical research.

The National Research Council finalized its report, "Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use" in 1997. The NRC Report acknowledges that the similarity between chimpanzees and humans "implies a moral responsibility for the long-term care of chimpanzees that are used for our benefit in scientific research." (page 9) The Report "enthusiastically supports the principal of retiring chimpanzees not needed for research or breeding to a low-cost, high quality life." (page 77) Chimpanzees, an endangered species listed on CITES Appendix I, share 98.4 percent of our genetic material.

The appropriation requested should be made available to an appropriate 501(c)(3) non-profit corporation, such as the Center for Captive Chimpanzee Care (CCCC), which would be capable, with such funds, of providing for the long-term humane treatment of chimpanzees ready to be retired. $7 million dollars would be used for initial construction and one year's operating expenditures; $1,547,600 would be available for the housing and care of 212 chimpanzees for one year at an estimated cost of $20 per chimp per day. Funds appropriated under this section which are not immediately expended for the facility construction and initial expenses could be set aside in an appropriate interest-bearing account to be used for operating expenditures after the first year.

Although it is unclear how many chimpanzees realistically could be available for immediate "retirement" to a sanctuary constructed under this appropriation, the NRC Report notes that "212 of the 1,000 animals might be released to public sanctuaries or other long-term care facilities." (page 74) Thus, it is this initial bench-

[79] Id. (citing P. Saigh, personal communication with the author, Feb. 1, 1995).
[80] Bremner, supra note 25, at 105.
[81] Id.
[82] Id.

mark figure which has been used to calculate the approximate initial chimpanzee retirement.

Similarly, it is difficult to assess the actual cost for the ongoing care of these individual chimpanzees. The NRC, in examining hypothetical sanctuary models, concluded that "for some plausible ranges of values, the models indicated net savings could be achieved from sanctuary construction." (page 60) A chimpanzee retirement sanctuary is a cost-effective way to house and care for chimpanzees no longer needed in biomedical testing.

Any facility funded under this appropriation must meet certain criteria: 1) retirement must be permanent and 2) once in the sanctuary, no harmful, invasive, or stressful research can be conducted on any chimpanzee (research that is solely observational in nature may be conducted).

The CCCC Board includes Jane Goodall, Ph.D. and Roger Fouts, Ph.D. In discussing the United States Air Force's divestiture of its chimp colony, Dr. Goodall noted that her "ultimate wish for the Air Force chimpanzees is the same as it is for all the other chimps in labs . . . to know the grass and sun, and to know freedom and peace." Dr. Fouts added: "The Air Force has an ethical obligation to honorably retire these involuntary recruits to a sanctuary where they can live out their lives in peace." Unfortunately, the lack of adequate funding for this sanctuary effort prevented the CCCC from gaining primary ownership of the Air Force chimps and may have resulted in the majority of them going to the Coulston Foundation, a chronic violator of the law (see page 3).

Additionally, the NRC Report acknowledges that the existing captive chimpanzee population "is more than adequate to meet research needs for at least five years" and therefore concludes that there should be a moratorium on breeding chimpanzees for at least five years. Following this wise recommendation, this Committee should not appropriate funds for the breeding of chimpanzees in laboratories or for biomedical research, nor should it appropriate any money that would ultimately be used in an experimental protocol which requires additional breeding of chimpanzees.

TAXPAYER DOLLARS SHOULD NOT BE PROVIDED TO THE COULSTON FOUNDATION, A CHRONIC VIOLATOR OF THE LAW

The New Mexico-based Coulston Foundation should be prohibited from receiving any funds appropriated by Congress as a result of its remarkable record of flagrant violations of even the most minimal standards of animal care under the Animal Welfare Act.

In 1993, three chimpanzees died in a housing facility maintained by the Coulston Foundation when failure to control the temperature caused the heat to rise to 140 degrees Fahrenheit. One year later, failure to provide adequate water led to the dehydration of 14 primates and the deaths of four of them. In that same year, the Coulston Foundation failed to provide adequate space for 37 primates; this deficiency in care was not remedied by the following year, and two years later, 27 of the 37 animals were still housed in unacceptable conditions.

In 1998, the Coulston Foundation was once again charged by USDA with violations of the Animal Welfare Act relating to the negligent deaths of two chimpanzees. According to the USDA Animal and Plant Health Inspection Service press release, Coulston failed to handle three sedated chimpanzees "in a manner that did not cause behavioral stress, physical harm, and unnecessary discomfort;" failed to provide adequate pre-procedural and veterinary care; failed to "maintain primary enclosures for nonhuman primates in good repair so as to protect the animals from injury and contain them;" failed to "store supplies of food for nonhuman primates in a manner that protects them from spoilage, contamination and vermin infestation;" failed to "clean and sanitize primary enclosure for nonhuman primates as required;" and the list, sadly, goes on.

As if this were not bad enough, the Coulston Foundation was charged in February of this year with three new chimpanzee deaths. According to USDA, Coulston's failure to "establish and maintain a program of adequate veterinary care, including the prevention, control, diagnosis, and treatment of diseases" resulted "in the unnecessary deaths of three chimpanzees known as Holly, Terrance, and Muffin." Michael Dunn, USDA's Under Secretary for Marketing and Regulatory Programs said of this case: "We have grave concerns regarding the circumstances under which several chimps have died at the Coulston Foundation."

The Coulston Foundation should not be rewarded for its egregious failures to comply with the law by continuing to receive millions of dollars in taxpayer-funded grant support.

$2 MILLION IS REQUESTED FOR RESEARCH ON REFINEMENTS IN PRIMATE HANDLING, CARE AND HOUSING TO PERMIT COMPLIANCE WITH THE FEDERAL ANIMAL WELFARE ACT

In 1985 Congress passed the Improved Standards for Laboratory Animals Amendment to the Animal Welfare Act. This new law included a mandate for a "physical environment adequate to promote the psychological well-being of primates." In addition, the law emphasized the importance of consideration of alternatives in projects involving the use of animals in potentially painful or distressful research. An often overlooked alternative is "refinement" in the conduct of research, and improving the training, housing and/or care provided to laboratory animals is an extremely worthwhile and achievable refinement.

Unfortunately, the spirit of these important components of the 1985 amendment are not being met in the majority of facilities which utilize primates. Though the amendment was implemented in 1989, most primates—by nature social creatures—remain isolated in single cages in the laboratory. In far too many cases primates have been provided with simple toys, that quickly loose their novelty and remain unused in a corner of the animal's barren cage. Much more needs to be done for primates to provide for their well-being. Additional research in this area is sorely needed.

In the 1950s R.A. Chance found that "the better the conditions of the animals' well-being—in housing, treatment and social situation—the lower the variance" in research results. If we use ethological sophistication to provide laboratory primates with the best physical and social environmental conditions for their well-being, we may be able to use fewer of them in research, and our results will be accurate and reliable.

In addition, primates used in research are commonly subjected to catching, handling, and restraint procedures that cause unnecessary excitation and distress. Such procedures include catching animals with nets, forcing animals into transport boxes with sticks or squeeze-back cages, physical immobilization during venipuncture or restraint in a monkey chair. A primate who experiences undue excitation or distress while being caught, handled or restrained for scientific data collection is no longer a suitable research model because its behavioral and physiological responses are not normative. Data collected from these subjects are likely to be biased and hence of little scientific value. Simple and safe alternative handling methods have been developed, but much more work needs to be done. Funding needs to be provided for this purpose.

We hope that $2 million can be designated for research specifically to improve the housing, handling and care of primates in the laboratory. Such research will provide numerous benefits to the animals and to the researchers. Better cared for laboratory animals will yield better research results.

TO ENSURE THE INTEGRITY OF RESEARCH AND PROTECT FAMILY PETS, AN NIH POLICY AGAINST ACQUISITION OF DOGS AND CATS FROM RANDOM SOURCE DEALERS IS NEEDED

In February of this year, the Department of Justice announced the conviction of nine individuals on charges related to theft of animals for sale to medical research. The ringleader, a random source animal dealer licensed by the USDA, sold hundreds of dogs to laboratories in California and Washington State including the University of Southern California (which received $99,419,542 from NIH in fiscal year 1998), Cedars Sinai Medical Center (which received $10,749,429 from NIH in fiscal year 1998) and the Seattle Institute of Biomedical and Clinical Research (which received $4,470,930 from NIH in fiscal year 1998).

Stolen pets have been purchased, experimented on and killed in research institutions that receive funds from the National Institutes of Health. Taxpayer dollars should not contribute to this unscrupulous trade. Random source dog and cat dealers are the problem. Though these dealers are licensed and inspected by USDA, the Department of Agriculture is unable to provide an assurance that the animals sold by these dealers are not stolen pets.

Random source dealers are not used to supply dogs and cats used for intramural research at NIH. This excellent example should be followed in providing funds for extramural research. Random source dealers should not be used as a source of animals for extramural research. Dogs and cats can be obtained from licensed breeders and from some municipal pounds. Therefore, we encourage you to include report language recommending that NIH discourage the acquisition of dogs and cats from random source dealers in extramural research projects. This is the only way to ensure that stolen pets including those acquired by deception, are not used in federally funded research.

I conclude with a statement provided by Dr. Robert A. Whitney, former Deputy Surgeon General, U.S. Public Health Service:

"I have an extensive background in this and other issues of public concern about the procurement and use of animals for biomedical research. Before becoming Deputy Surgeon General in 1992, I served as Director, National Center for Research Resources (NCRR) of the National Institutes of Health (NIH). In my 22 years at NIH I was responsible for production, procurement, and care of animals used in NIH intramural research. I also served as chairperson of the NIH Animal Care and Use Committee, Chairman of the U.S. Government Interagency Research Animal Committee (IRAC), and Director, NIH Office of Animal Care and Use. At NIH, the use of dogs from Class B dealers, otherwise known as random source dogs, ceased many years ago.

"Over the past 25 years I have been involved in the development and update of most of the federal policies and regulations governing appropriate care, use, and welfare of animals used in biomedical research. This experience has led me and many of my colleagues to believe that our inability to guarantee the quality of procurement and care of animals from Class B dealers creates many problems in public perception for the biomedical research community, and potentially in the research itself. Despite the small number of animals obtained from these sources, their use portends many more problems than the benefits which might be derived."

Thank you.

PREPARED STATEMENT OF MELISSA HALEY, EXECUTIVE VICE PRESIDENT, CHILDREN'S HEART FOUNDATION

Distinguished Subcommittee Members: On behalf of the Children's Heart Foundation and all that are suffering from congenital heart defects we enter this testimony for consideration for the fiscal year 2000 budget hearings. We ask that the members of this committee will grant fifty million new dollars to the NIH earmarked for congenital heart defects, America's number one birth defect.

In these next few pages you will find facts on CCVM (congenital cardiovascular malformations) and stories of families who have lived with these life-threatening conditions. One of these families has lost the battle and another still carries the hopes of survival. You will also hear from two cardiologists. Dr. Marla Mendelson, a cardiologist from Northwestern Hospital in Chicago treats teens and adults with congenital heart defects, and Dr. Pedro J. del Nido, Cardiac Surgeon Harvard Medical School. Dr. del Nido speaks to the importance of medical cardiac devices needed for children and tissue engineering.

Upon searching the NIH for projects in congenital heart defect research, I have found statistics that are enlightening.

—Eight percent of all deaths during the first year of life are caused by congenital cardiovascular malformations (CCVM). Approximately 30,000 babies are born each year with this anomaly and 2,900 of them will die before their first birthday.

I am a mother who has lost her child to congenital heart defects. My name is Betsy Peterson. My son Sam was born with complex congenital heart defects. Sam had his first surgery at three days old. One could only imagine the pain of seeing your newborn, a helpless baby, after having such a terribly invasive operation. As Sam grew he needed more surgeries, four in all. During these surgeries Sam was given a pacemaker, valve replacement and shunt replacements. Before his untimely collapse and subsequent death he was facing a fifth surgery. This one he was very afraid of having. He said "Mom, I really don't want to go through the next surgery". Through all Sam's health problems, he was an active vital part of his school and church and he had many close friends. Sam was a soccer player and enjoyed golf. He was a friendly child who always felt the pain and loneliness of others. Sam had a life. He will never be forgotten and his memory lives on in the dedication of the Children's Heart Foundation and the mission to eradicate Congenital Heart Defects.

Doctors do not know why my son Sam was born with these anomalies or why he suddenly collapsed at school one day at the age 8. Sam died 12 days after that collapse due to multiple organ failure. After much investigation, I learned that there was no national group strictly devoted to raising money for congenital heart research. It was upon his untimely death, January 3. 1995 when our family was trying to decide where memorial gifts should be directed, that I learned congenital heart defects are America's number one birth defect. I was shocked to learn that approximately one out of every one hundred and fifteen babies is born with congenital heart defects.

—Forty two percent of all birth defects are caused by CCVM. All these congenital defects are equally distributed among all populations in the U.S. Many children who survive infancy go on to suffer in their older years. They are forced into

a life of dependency on medications, medical procedures and repeated open-heart surgeries. These children often have impaired physical and social development.

A mother of an adolescent testifies as to her child's daily life. " My daughter, Jessica will be 16 years old on June 7, 1999. Jessica has a hyperplastic left heart. She lacks energy and is often more prone to getting sick than the typical child. Her recoveries from illnesses also seem to take longer. Jessica has missed a lot of school in the last three years and a lot of socialization. She is on three heart medications in addition to one she takes for migraines. It is difficult to medicate her for pain because one of her heart medications is a blood thinner. Although we try to maintain a positive atmosphere as much as possible, the stress on the entire family has been considerable. We have been lucky until now, financially, most of our costs have been covered by insurance. However there are still co-pays on medicine, doctors visits, physical therapy, counseling and rehabilitation. All of these are extra expenses a typical family may face. Jessica had four heart surgeries by the time she was thirteen and a half. From the time she was five until she was thirteen her heart was massively enlarged. Toward her thirteenth birthday, her health began failing and it was determined that she needed either a revision of her third surgery or a heart transplant. We chose the revision, but that procedure would not have been available if we had had to make that decision three years before. Because of all the research being done, my daughter is alive today. Research can save many lives, as it has saved my daughter, but sometimes it can take us only so far. That is why it is so important that the research in congenital heart defects continue to be supported. For a long time we were "even with the research". Somehow Jessica lasted until a new technique was developed, but again, at this point we are "even with the research". I believe that congenital heart research has been seriously neglected. I teach special education and many of my students also suffer with congenital heart defects, in addition to other disabilities.

Jessica knows that someday she will probably need a transplant. I think she has known that on some level for a long time. I can imagine her fears and the uncertainty she must feel about her life. She is a very brave girl and I know that she has been a gift for me, but a gift that I may not be able to keep."

—Deaths due to CCVM occur throughout childhood, adolescence and young adulthood. Thirty six hundred children under age 15 die annually from these defects. In addition to the incredible impact on the families, the social costs are great as well. In 1992 nearly $500 million was spent to pay for 44,000 hospitalized children who were under 15 years old. Because so few children lived long enough to have children of their own, genetic studies have been difficult. However research has now come to the conclusion that most CCVM occurrences are caused by gene defects. According to information provided by the NHLBI, genes may be the direct cause for at least 8 different structural heart defects. The discovery of causes such as genetic links and their resultant new procedures will help these children live more normal lives.[1]

Dr. Marla Mendelson writes of her experiences as a cardiologist. "Congenital heart disease may be most often diagnosed during childhood, but it is not a childhood illness. The ramifications of having been born with congenital heart disease may have lifelong effects. Although it is true that the tremendous advances in surgery for congenital heart disease permit the child to achieve adulthood, he or she may be not be cured. Often new problems emerge and require medical or surgical intervention long after childhood. This may be as simple as a pacemaker or as complex as cardiac transplantation.

The child born with heart disease spends his childhood in the hospital as a patient, a role few understand until middle age or beyond. After surgery and adolescence under the watchful eyes of parents and physicians, he or she may wish to walk out of the Children's hospital and never look back. After a very abnormal childhood these patients long to be like everyone else. They want to work, have fun with their friends, marry and have families. But these simple aspirations may not be easily attainable. Finding a job may not be a problem but healthcare benefits are not often available. These people have the "original" pre-existing illness as they were born with their heart disease, and may be disqualified from health coverage or even life insurance. Therefore they are faced with the dilemma of working but having no health coverage or declaring themselves to be disabled.

The desire to have a family may not be easily realized for these patients. After seven surgical procedures, a young woman only wanted to be like her friends. She wanted to participate as a dancer in local Community Theater with her husband.

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[1] NIH Guide: Gene Nutrient Interactions in the Pathogeneses of Congenital Heart Defects p.2 Backround.

But when evaluated for the safety of pregnancy, concerns about her welfare were raised. Not wishing to further compromise her own health, she adopted a child from Eastern Europe.

A forty five year old woman once told me she had had congenital heart disease but had surgery and was discharged from the children's hospital at age eighteen, never to return. I asked her whether she had received any advice regarding what she could expect in life and that she should have periodic evaluations. She stated, "They were just happy I made it to eighteen! They never expected me to live this long'. We are rapidly acquiring data on these survivors because although our expectations have increased, we still have a great deal to learn."

—Dr.Pedro J. del Nido pinpoints some of the most urgent research needs for pediatric heart patients. Dr. del Nido stresses that while many advances have been made in bioengineering, children have not been the beneficiaries. He cites the specific example of the mechanical heart assist device. There are several pumps available for adults but none for pediatric patients, where the need is so great. Another area of need is in tissue engineering. This is the use of a child's own tissue to replace defective structures such as heart valves and blood vessels and even the whole heart. These capabilities most importantly would then eradicate the need for prosthetic devices and transplants. Genes may be the cause of at least eight different congenital heart defects. Dr. del Nido urges Biomaterials to be developed to help in the delivery of gene therapy intercellular delivery.[2]

Individuals and grassroots efforts can do only so much. Congress must take on this effort and increase appropriations. We implore this committee to grant an increase of fifty million new dollars to the fiscal year 2000 budget earmarked to the NIH for congenital heart defects research. We thank you for your attention to our request.

Prepared Statement of Morgan Downey, Executive Director, American Obesity Association

Mr. Chairman, my name is Morgan Downey. I am testifying today as Executive Director of the American Obesity Association which was founded to serve as an advocate for the millions of persons in this country suffering with obesity and as a person with obesity.

Mr. Chairman, I come before you today to discuss the greatest neglected public health crisis in this country—obesity. Unfortunately and tragically this neglect also occurs in the world's premier biomedical research organization, the National Institutes of Health.

During this last year, the American Obesity Association was actively involved in discussions regarding NIH priority setting procedures. I testified before the Institute of Medicine Committee examining this matter and closely reviewed its report and NIH's own statements on setting priorities and its meetings concerning establishment of the Council of Public Representatives. It is my conclusion that NIH does not have any meaningful priority setting procedure and that current steps such as the Institute planning meetings and COPR, are meant to merely support the existing structure.

The proof is this conclusion is simple. If NIH followed its own priority setting procedures, or that recommended by the Institute of Medicine, obesity would have to receive far, far greater funding than it does.

The National Institutes of Health has identified six criteria for consideration in establishing research priorities. They are:

1. Number of people who have a particular disease,
2. Number of deaths caused by a disease,
3. Degree of Disability produced by a disease
4. Degree to which a disease cuts short a normal, productive, comfortable life,
5. Economic and Social Costs of a disease,
6. Need to act rapidly to control the spread of a disease.

(Setting Research Priorities, NIH, 1997)

To this list, the Institute of Medicine recommended adding:

(7) the burden and cost of disease, and

(8) the impact of research on the health of the public.

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[2] Pedro J. del Nido M.D. Harvard Medical School: Excerpt taken from the draft proposal for Pediatric Bioengineering Initiative to be delivered to the U.S. House Appropriations Committee for the fiscal year 2000 budget hearings.

Obesity, when compared to other diseases and conditions, meets or exceeds all of these criteria and yet it is treated like an orphan disease at NIH. Consider the following:

1. NUMBER OF PEOPLE WHO HAVE A PARTICULAR DISEASE

The prevalence of obesity in the United States has increased from 25 percent of the adult population in the second National Health and Nutrition Examination Survey (NHANES II, 1976 to 1980) to approximately 35 percent of the adult population in the NHANES III survey (1988 to 1991). This represents an absolute increase in prevalence of 10 percent and a relative increase of 40 percent.

Increases in obesity have occurred across virtually all ethnic, racial, and socioeconomic populations and all age groups. Certain minority populations, particularly minority women, have been found to be at the greatest risk for obesity and hence, its co-morbidities. In NHANES III, nearly 50 percent of all African-American and Mexican women surveyed were obese. Within the 45- to 55-year-old age group, the prevalence of obesity was between 60 percent and 70 percent.

An estimated 97 million adults in the United States are overweight or obese, a condition that substantially raises the risk of morbidity from approximately 32 conditions including, in part, birth defects, hypertension, dyslipidemia, type 2 diabetes, coronary heart disease, stroke, gallbladder disease, osteoarthritis, sleep apnea, respiratory problems, and endometrial, breast and colon cancer. Higher body weights are also associated with increases in all-cause mortality.

To put these figures in context, consider that there are 600–700,000 persons affected with HIV/AIDS, 8 million with cancer, 16 million with diabetes, 22 million with heart disease and 58 million with serious health risks from obesity.

2. NUMBER OF DEATHS CAUSED BY A DISEASE,

Poor diet and sedentary life style are responsible for between 300,000 and 587,000 deaths a year, making it the second leading cause of preventable death after tobacco. The figure of 300,000 to 587,000 deaths should be compared to 400,000 deaths from tobacco, 100,000 from alcohol, 90,000 from microbial agents, 60,000 from toxic agents, 35,000 related to firearms, 30,000 due to sexual behavior, 25,000 from motor vehicles, and 20,000 from illegal use of drugs. (McGinnis JM, Foege, WH, Actual Causes of Death in the United States, JAMA, 1993; 270:2207–2212)

3. DEGREE OF DISABILITY PRODUCED BY A DISEASE

Many persons with severe levels of obesity are compromised by functional limitations so severe that their ability to engage in significant gainful occupations is lost or diminished. Obesity is a causal factor for some 30 diseases or conditions many of which are incapacitating, such as complications from diabetes, arthritis and heart disease. Individuals at a high level of obesity often experience musculosketal, cardiovascular, peripheral vascular and pulmonary complications which make gainful employment impossible.

4. DEGREE TO WHICH A DISEASE CUTS SHORT A NORMAL, PRODUCTIVE, COMFORTABLE LIFE

Mortality and morbidity from obesity increase in proportion to increases in excess weight. One study concluded that, "obesity is strongly predictive of mortality from all causes combined, cardiovascular disease, and some cancers. (Solomon CG, Manson JE, Obesity and Mortality: a Review of the Epidemiologic Data, Am J. Clin Nutr. 1997; 66 (suppl) 1044S–1050S) Deaths from obesity appear to peak around age 75. This may be due to several causes but it appears that persons who are less resistant to the health effects of obesity die off before old age.

5. ECONOMIC AND SOCIAL COSTS OF A DISEASE

According to data compiled by the World Health Organization International Obesity Task Force, the economic costs of obesity are 3 percent to 8 percent of the total health care expenditures in the United States and Europe—proportions at least as great as those for all cancer and AIDS.

The total costs attributable to obesity from just a few of the conditions it causes amounted to $99.2 billion dollars in 1995. Approximately $51.64 billion of those dollars were direct medical costs. The cost of lost productivity attributed to obesity was $3.9 billion reflecting 39.2 million days of lost work, 239 million restricted-activity days, 89.5 million bed-days, and 62.6 million physician visits attributable to obesity in 1994. (Wolf AM, Colditz GA, Current Estimates of the Economic Cost of Obesity in the United States, 1998)

6. NEED TO ACT RAPIDLY TO CONTROL THE SPREAD OF A DISEASE

Obesity is increasing rapidly in the adult, child and adolescent populations. Approximately 11 percent of children and adolescents were overweight in 1988 to 1994, and an additional 14 percent had a BMI between the 85th and 95th percentiles. The increases occur across all age, ethnic and gender categories. Overweight in adolescence predicts overweight in adulthood and adverse health effects in adulthood.

Among women age 30–39, obesity has increase 53 percent in 34 years or 1.5 percent per year.

Globally, the picture is the same. The increase in obesity is a world-wide phenomenon. Obesity has been described by the World Health Organization as an "escalating epidemic" and "one of the greatest neglected public health problems of our time with an impact on health which may prove to be as great as smoking." (Consultation on Obesity, Geneva Switzerland, World Health Organization, June 3–5, 1997)

7. BURDEN OF DISEASE

One study found that, relative to U.S. population norms, obese persons seeking university-based weight loss treatment reported substantial decrements in Health Related Quality of Life measurements, that the impact of obesity on HRQL varied with severity of obesity, and that functional disability among obese persons due to bodily pain was particularly common—comparable to that of chronic migraine sufferers. (Fontaine KR, Health-Related Quality of Life in Obese Persons Seeking Treatment. J. Fam Pract, 1996, Sept; 43(3):265–279). In addition, persons with obesity are subject to tremendous discrimination and stigma in our society. This has a special adverse impact on children and adolescents.

8. THE IMPACT OF RESEARCH ON THE HEALTH OF THE PUBLIC

There is no question that the American public is extremely eager to deal with their weight problems. Unfortunately, the federal government and the National Institutes of Health have assumed little responsibility for the transmission of accurate, evidence-based research information. There the public's interest is too often met by tabloid type announcements of miracle cures, quick-fixes and magic bullets. Studies on successful prevention approaches and interventions useful for important subpopulations are urgently needed. In addition, the important molecular genetic studies on obesity will not be useful if better population studies do not occur. Programs for study of multiple therapies and for the effectiveness of treatment approaches are urgently needed.

What are we to think of a disease which overwhelming meets all of NIH's own criteria for research priorities (and the IOM suggested criteria) and yet receives a pittance of funding and whose only organizational home is a program office within one of three branches in one of 6 Divisions in the National Institutes of Diabetes and Digestive and Kidney Disorders (diabetes being one of 30+ conditions caused by obesity). Without disparaging in any way the support of NIDDK, it is fair to ask where are the neuroscience research institutes who study brain and behavior ? Where are the institutes studying child health and aging? Where are the other Institutes whose core diseases are caused by obesity, such as the Heart Lung and Blood Institute and the National Cancer Institute. Where are the Institutes focused on substance abuse, addiction and mental health?

Either NIH has engaged in some process which has met and discounted all the scientific data on obesity or it has no meaningful process in contraction of its own statements. I submit that the latter is the appropriate explanation.

Unfortunately, the state of obesity research at NIH further belies its own self-descriptions of engaging in "basic research." Patient advocates are often told that they must understand that all research cannot be labeled for their particular disease. Rather, NIH engages in "basic research" which is fundamental to many disease states. One might think from this that NIH would research causes more than symptoms. But this is not the case. Diseases or conditions for which obesity is a recognized and independent risk factor receive far more generous funding than the causative condition itself—obesity. For example NIH expects in fiscal year 1999 to fund diabetes research at $449 million and hypertension research at $194 million or combined 400 percent greater than obesity research (est. $144) even though most diabetes (90–95 percent of Type 2 Diabetes) and hypertension (75 percent) is caused by obesity. Can this be called a commitment to basic research?

Therefore, the American Obesity Association urges the Committee to commission a study by the Institute of Medicine to (A) recommend scientific opportunities for research on obesity (B) recommend the optimal organizational structure at the Na-

tional Institute of Health for obesity research and (C) identify the required budgets to support an aggressive effort to maximize current scientific opportunities in the study of obesity as well as to engage in urgently needed public education campaigns.

Given the growing prevalence of obesity and its clear threat to health, any long term investment which tries to improve public health or lower health care costs without accounting for the impact of obesity is wasted money.

PREPARED STATEMENT OF JERRY FREUNDLICH, FOUNDER AND PRESIDENT, CURE FOR LYMPHOMA FOUNDATION

The Cure For Lymphoma Foundation (CFL) a nationwide, not-for-profit organization dedicated to funding research and to providing support and education for those whose lives have been touched by Hodgkin's disease and non-Hodgkin's lymphoma appreciates the opportunity to participate in the fiscal year 2000 process.

We endorse the testimony presented and recommendations made by Robert I. Handin, M.D. of the American Society of Hematology (ASH) and Richard J. Boxer of the Lymphoma Research Foundation of America (LRFA). Specifically, we urge Congress to adopt lymphoma-specific language for increased lymphoma research at the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and the National Institute of Environmental Health Sciences (NIEHS).

The following is the requested report language:

NCI

Lymphoma.—Lymphoma is the second fastest growing cancer by rate of incidence. It is estimated that approximately 88,600 Americans will be diagnosed with lymphoid malignancies in fiscal year 1999 with a 50 percent mortality rate. [Of which 64,000 persons will be diagnosed with Hodgkin's disease and non-Hodgkin's lymphoma (NHL).] We are currently making strides in the fight against cancer, as evidenced by the decline in some cancer rates. However, the rate of incidence of lymphoma is actually increasing while little is known about the disease including its cause and effective treatment. The Committee encourages NCI to increase lymphoma research conducted at NCI, promote new innovative research models based on collaborative methods to maximize current lymphoma research conducted at NCI, collaborate research efforts with NIEHS to explore environmental factors as causes of lymphoma, and collaborate research efforts with CDC to promote increased research on the cause of lymphoma. The Committee also encourages NCI to consider exploring research in currently incurable lymphomas such as low-grade and aggressive incurable lymphomas.

NIEHS

Lymphoma.—Lymphoma is the second fastest growing cancer by rate of incidence. It is estimated that approximately 88,600 Americans will be diagnosed with lymphoid malignancies in fiscal year 1999 with a 50 percent mortality rate. (Of which 64,000 persons will be diagnosed with Hodgkin's disease and NHL.) The Committee encourages NIEHS to collaborate research efforts with NCI to better understand environmental factors, which may contribute to the cause of the disease and expand research in collaboration with NCI to expand its knowledge on this disease.

CDC

Lymphoma.—The Committee encourages CDC to expand its support into the potential of environmental factors associated with lymphoma and encourages continued and expanded collaborative research efforts with the National Institutes of Health (NIH).

Your Subcommittee endorsed similar language last year that was adopted as part of Senate Report 105–300. We ask that you continue your support in funding the research essential to improving treatments and finding a cure for lymphoma. We ask this because the causes of lymphoma remain unknown.

On April 21, 1999, CDC, NCI, and ACS released an annual report on cancer, which found that between 1990 and 1996 NHL was one of two cancers increasing in incidence and death rates while all other cancers declined. In 1999 alone, the American Cancer Society (ACS) estimates that over 64,000 people will be diagnosed with lymphoma, approximately 56,000 with NHL and 7,200 with Hodgkin's disease. In addition, over 27,000 people will die from lymphoma, approximately 25,700 from NHL and 1,300 from Hodgkin's disease. Furthermore, lymphoma is the third most common childhood cancer and comprises 10 percent of all childhood cancers in children under the age of 15.

Almost eight years ago, I was diagnosed with large cell immunoblastic lymphoma. I was fortunate, because there was a chemotherapy protocol that worked for me. I was treated very aggressively with "CHOP" chemotherapy and radiation. From the very beginning I knew that my survival was a result of innovations in research that led to the development of CHOP. In 1994, I founded CFL. CFL was established with the intent to fund lymphoma research. Without new and innovative research, the rate of increase of lymphoma will undoubtedly continue to rise. We thank you for your consideration in this matter. Should you have any questions, please feel free to contact us.

PREPARED STATEMENT OF SHARON L. MONSKY, CHAIRMAN, BOARD OF DIRECTORS, SCLERODERMA RESEARCH FOUNDATION

INTRODUCTION

Mr. Chairman and members of the Committee, I thank you for the opportunity to present testimony before you today and for all you have done in the past to support the National Institutes of Health and its mission to advance the most important and most promising medical and scientific research to improve the health of our great nation.

I have come to you with but one request, which I dare say is different than any other requests you have heard in these chambers: I want you to help put me out of business.

For a decade now, I have been the leader and champion of what, by anyone's standards, must be considered a very successful enterprise. It has grown quickly and is on the verge of great discoveries and unprecedented success in its niche. But, I have a very big problem: my clients are dying.

Mr. Chairman, I am in the business of finding a cure for a disease which affects over half a million Americans, over 80 percent of them are women in the prime of their lives. More people are affected by this disease than muscular dystrophy, multiple sclerosis, or cystic fibrosis. The truth is that it is at least as disabling, more ugly, disfiguring, and even more deadly than any of these diseases. Unfortunately, most people have never heard of scleroderma, and there is relatively little being done to find a cure.

THE DISEASE: SCLERODERMA

I had no idea what I was up against almost seventeen years ago when I was diagnosed with scleroderma and given only a few short years to live. Scleroderma means "hard skin." However, it is not just a disease of the skin. It is a chronic, degenerative, auto-immune disease that leads to the overproduction of collagen in the body's connective tissue. The overabundance of collagen hardens the connective tissue and destroys the organs involved...the vital organs we need to survive.

Scleroderma can affect patients differently. It can be quite individualized. In about half the cases, the skin is the primary organ affected. In the other half, patients are diagnosed with systemic sclerosis, which typically involves the vital internal organs: kidney, heart, lungs, and/or the gastrointestinal tract. The great majority of patients with systemic sclerosis die within seven years of their diagnosis. There is no known cause or cure for scleroderma. In addition, there are no FDA approved therapies for any major symptom of this painful, ugly and often deadly disease.

I am here today, thanks to the love and support of my three miracles, my children, and the renewed commitment and inspiration I continue to receive from patients, volunteers, and all those struggling with me on a daily basis to conquer this disease. I know in my heart the same thing that Harold Varmus knows in his head: this disease is curable. It is curable because our ability to diagnose it has advanced so significantly, because we have gained valuable insight into the basic science and pathogenesis of the disease, because our biomedical technology is now quite suited to the undertaking, and most of all, it is curable because the Scleroderma Research Foundation will not stop and I will not rest until we succeed.

THE SCLERODERMA RESEARCH FOUNDATION

The Foundation is the only organization in the country dedicated exclusively to finding a cure for scleroderma. We have made great strides in a very short period of time because we are in business to go out of business. Every day we work backwards from what is necessary to find a cure. Our research program is built on a concept of Cure Advocacy: an innovative approach which stands traditional research on its head by progressing along a well-focused path, sharing all research results

immediately, rather than waiting for publication and review, and by working across traditional medical, academic and public-private boundaries.

Dr. Regis Kelly, Chairman of the Department of Biochemistry and Biophysics at the University of California, San Francisco, says "every $100,000 invested in this kind of research can produce $1 million in results compared to the usual methods." As Dr. Kelly explains, "What is revolutionary in my experience is a streamlined, rational, planned system of research to get the fastest results in the most efficient way possible—the biggest bang for the buck—instead of the typical piecemeal approach."

Dr. Bruce Alberts, President of the National Academy of Sciences, predicts that our approach "will serve as a model for future medical and scientific research, because of its unprecedented, unified plan of attack."

RESEARCH APPROACH AND PROGRESS

The first test of this new approach was in the November, 1992, opening of the nation's first collaborative scleroderma research center, located in San Francisco. The Bay Area Scleroderma Research Center is a "center without walls," bringing together outstanding researchers and advisors from Stanford University, University of California, San Francisco, and several private Bay Area biotech firms. In the last six and a half years, the Center has made unprecedented progress in establishing accurate diagnostic measures, developing disease modes, understanding the role of key cells in the disease onset, and discovering significant breakthroughs in the understanding of molecular mechanisms that underlie fibrosis (the hardening of the skin). This research team has consistently produced exciting findings. Just in the last six months, they have identified a type of collagen, one that was previously not recognized as important in scleroderma that was significantly increased in all the scleroderma fibroblasts. The team is also pursuing, quite successfully, an exciting new technology called GeneChip analysis to begin to work on complex collagen issues. Although it is unlikely that a single gene will be identified that causes scleroderma per se, an overall picture of what genes are turned on or off in scleroderma fibroblasts can be put together. From this much more complete picture of the fibroblast, we hope to reconstruct the events that occur in the disease. With the support of biotechs, and top advisors on a pro-bono basis, our investigators are able to make successful strides quite quickly.

The interest generated within the scientific and medical research community afforded the Foundation an opportunity to create an additional East Coast Center, opened in August of 1994, in the Washington D.C./Baltimore area, with participation from Johns Hopkins University, the University of Maryland, the National Institutes of Health, and Baltimore Biotech. This second center has expanded to include Ohio State and is focused on understanding early vascular and skin changes in scleroderma patients, with special emphasis on helping to advance therapeutic techniques to slow development of the disease process. Again, this team also has been very successful. One of our leading investigators recently received a grant from the National Institute of Arthritis and Musculoskeletal and Skin Diseases for work specific to scleroderma through the competitive grant process. Another investigator has begun to define features that unify the autoantigens targeted by the immune system in scleroderma. An additional investigator has discovered that a specific response of the smooth muscle cell's genome (the DNA blueprint of the cells) could be responsible for the behavioral switch of these cells.

Since the Scleroderma Research Foundation began in 1987, it has funded over $4 million in research projects. Through Cure Advocacy, the Foundation has brought together private industry and academia to direct and manage our efforts. More importantly, the Foundation is no longer just encouraging new and exciting young researchers into the field with special grants; many young rising stars have dedicated their careers to the basic science of scleroderma. It is no longer simply focused on finding the best medical and scientific research; it is indeed in the leadership position of nurturing and directing the finest research. Most importantly, the Scleroderma Research Foundation is now driving the science in the direction of a cure.

PARTNERSHIP

The Scleroderma Research Foundation has successfully met the challenge of raising private funds, bringing together the top scientists, and targeting the most direct approach to finding a cure for chronic illness. The Foundation has two very successful and productive Scleroderma Research Centers. Yet much more needs to be done.

In order to succeed, we desperately need the federal government to become a full partner in our investment in a cure. With current budget constraints and other established priorities, we are not willing to simply act as another advocacy organiza-

tion fighting over shares of the pie, and we certainly do not want to take needed funds away from other deserving areas of health investigation. However, we do feel very strongly that scleroderma is an overlooked but important health problem facing a half a million Americans, primarily women. The need is clear.

Most importantly, our collaborative approach to research has proved to be sound in both a research and business sense. We have leveraged $4 million privately raised dollars into some of the most exciting research ever in the field. Our scientific advisors and investigators are amazed at what they can accomplish using this directed, collaborative approach working across traditional institutional and communication barriers. If nothing else, it is worth an exploratory investment from Congress to see if this model can really fulfill the prediction of Dr. Bruce Alberts, and change the way every disease is eventually research.

Mr. Chairman and members of the committee, I am here today to ask Congress to recommend that the NIH become a partner in cure advocacy. The National Institutes of Health should fully participate in our multi-institutional, multi-disciplinary efforts to find a cure for scleroderma and other chronic illnesses.

We have for several years requested in testimony to this committee, that Congress maximize the value of each federal dollar invested in biomedical research and demonstrate its willingness to become a partner in the search for a cure by matching the Foundation's investments in scleroderma research. We are requesting that Congress fund $4 million for this method of research through NIAMS or another appropriate NIH institute. There are many excellent opportunities for progress that are being missed in the current environment, and we believe it has nothing to do with any lack of commitment on the part of NIAMS. The institute director, staff, and investigators appear to be equally excited about the innovative approach we have brought to scleroderma research. They simply need the wherewithal to act and make a relatively small investment compared to total research allocations, but with a potentially huge rate of return.

The Foundation continues to forge ahead each year with symposiums to determine the priorities for the scleroderma research campaign and to attract the best and brightest scientists to support our research efforts. In addition, we have continued to request that a national registry for scleroderma patients be created. We are not asking for a handout in this area, simply partnership. We have forged ahead on our own to establish a registry of tissue and lymphocytes on both the east and west coasts to assist investigators in the basic science of scleroderma. A commitment by NIAMS to create a national registry and work with us would achieve significant results very quickly and assist those involved in clinical and laboratory research on this disease.

Finally, we ask that the committee demonstrate support for NIAMS and increase its appropriation to encourage its future growth and leadership in disease research.

CONCLUSION

Adopting and fostering a collaborative research approach to solve chronic illness is more important than appropriating millions of dollars for any one disease. The Scleroderma Research Foundation has taken the initiative to bring together the best of business and science in a fast-track search for a cure. We are asking you to join in this results-oriented partnership through concentrated federal support. By matching our investment in a cure, becoming our partner, and adequately funding NIAMS, Congress can leverage the most results from its research appropriations, and provide hope to hundreds of thousands of people who struggle daily with this terrible disease.

PREPARED STATEMENT OF TRAVIS THOMPSON, PH.D., DIRECTOR, JOHN F. KENNEDY CENTER FOR RESEARCH ON HUMAN DEVELOPMENT, VANDERBILT UNIVERSITY; CHAIRMAN, MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES RESEARCH CENTER DIRECTORS ORGANIZATION

Mr. Chairman and Members of the Committee: I am Dr. Travis Thompson, Director of the John F. Kennedy Center for Research on Human Development. It is a pleasure to submit this testimony on behalf of the network of 14 Mental Retardation and Developmental Disabilities Research Centers sponsored by the NICHD. The NICHD is at the forefront of our national effort to prevent mental retardation, learning disabilities, autism and related disabilities. The research sponsored by the NICHD has led to new treatment and educational methods, as well as more cost-effective habilitative strategies. The Mental Retardation and Developmental Disabilities Branch administers the 15 Mental Retardation Developmental Disabilities Research Centers (MRDDRCs) which are the focal point of our national effort to over-

come problems of human development. This program includes research designed to solve problems unique to specific disabilities (e.g. Fragile X or Rett's Syndrome), as well as more general strategies that cut across numerous disabling conditions (e.g. problems of early language development). Fetal Alcohol Syndrome was first identified by researchers at one of the NICHD's MRDDRCs, and the first gene therapies for a developmental disabilities are being developed at two of the MRDDRCs (Duchene's Muscular Dystrophy and OTC deficiency). Promising programs of research on the genetic and metabolic disorder underlying Rett's Syndrome, and brain mechanisms underlying dyslexia are being done within the MRDDRC network. In the past several years a major research network has been established by the NICHD to address the causes, prevention and treatment of autism, and many of the researchers in that network are based at the MRDDRCs. The NICHD is a leader in research to understand the causes, treatment and the development of more effective educational strategies for children with learning disabilities. I would like to share with you several of these initiatives in more detail.

BRAIN PLASTICITY AND EARLY EXPERIENCE:

Amazing advances are occurring in our understanding of the developing brain and it's impact on children's intellectual and emotional development. For over 3 decades we have known many children profit from early intervention, but we have not understood why these effects are lasting in some cases but temporary in others. Laboratory animal studies have shown changes in brain weights and organization when young animals were exposed to enriched early experiences. Recently, new evidence, discovered through work at the Rose F. Kennedy Center at the Albert Einstein College of Medicine in New York, indicates that the rate of formation of new brain connections reaches its peak between 18 months and 48 months of age . . . the time during which language development is occurring most rapidly. Further study at the Mental Retardation Research Center at UCLA showed that the availability of newer brain imaging methods such as Magnetic Resonance Imaging (MRI) reveals localized metabolic rate changes during this same period. These various lines of evidence, combined with studies of early intervention in autism and language development in poor and more affluent young children, such as the study at the MRDDRC at the University of Kansas, all point to the critical role of differential neuroplasticity in early experience leading to permanent changes in cognitive abilities. This is one of the most important areas of research in brain-behavior relationships to be exploited in the next decade, and we urge that a high priority be placed on this topic.

FUNCTIONAL NEUROIMAGING, ELECTROPHYSIOLOGY & BRAIN-BEHAVIORAL PROCESSES

New technologies permit brain scientists to study the brain of developing children at work, as well as providing insights into the way the brains of individuals with various developmental disabilities differentially process information. Functional Magnetic Resonance Imaging, Positron Emission Tomography and Quantitative Topographical EEG and Event Related Potential technologies have enormous promise in furthering our understanding of the relation between brain function and behavior among people with developmental disabilities. These new tools provide critical leads for differential diagnosis as well as documenting site and mechanisms by which treatments produce behavioral and cognitive outcomes.

Researchers based in the network of MRDDRCs are studying brain structure and function among individuals with behavioral and developmental disabilties. The MRDDRC at the University of Washington in Seattle is using electrophysiological recording methods to understand differences in brain function of children with autism. Others at the Seattle MRDDRC have used Spectroscopic MRI to measure brain activity of dyslexic and non-dyslexic children while performing language tasks and non-language hearing tasks. Th ey found dyslexic children had higher brain metabolic activity levels in specific brain areas compared with a control group during a phonological listening task. This information, together with recent genetic findings holds great promise of a breakthrough in understanding the basis for certain forms of reading disabilities. Researchers at the Waisman Center at the University of Wisconsin are exploring the role of dysfunction subcortical brain areas in the emotional and behavior disorders seen in developmental disabilities. Universities find it extremely difficult to keep pace with the cost of these rapidly changing technologies without federal assistance. The NICHD has a critical role to play in assisting in updating and replenishing this critical research infrastructure.

GENETIC & BEHAVIORAL RESEARCH

Learning disabilities

Clinicians have recognized for some time that reading disabilities run in families. Fathers who had reading problems in school are likely to have sons with reading disabilities. Dr. Bruce Pennington and his colleagues at the MRRC at the University of Colorado have identified four chromosomes as candidates for sites for genetic abnormalities associated with reading disabilities. Armed with this information, geneticists are better prepared to identify the proteins these genes produce and to study their role in abnormal brain development. This is a critical step in identifying how the brain abnormality originally developed and therefore a key to preventing reading disabilities.

Fragile X syndrome

NICHD research has helped solve a major puzzle contributing to one of the leading causes of inherited mental retardation in the United States, Fragile X syndrome. These findings have also opened up a window to understanding the genetic basis for other neurological diseases including Rett syndrome, Down syndrome and Huntington's disease. Fragile X syndrome is due to a defect on the X chromosome, which means it is twice as common in male infants as female infants, affecting one in every 4,000 boys. Children with Fragile X syndrome have impaired learning ability, they are often painfully shy and prone to severe anxiety difficulties and some display serious behavior problems. Often girls with Fragile X are less severely affected, frequently having a learning disability affecting reading. NICHD sponsored research identified an abnormal repetition of a DNA sequence near the tip of the X chromosome that creates the "fragile" site which is responsible for the defect. The more repetitions of this sequence, the more severe the symptoms. Subsequently, it has been discovered that this same process of repeated DNA sequences is also found in Huntington's Disease, myotonic dystrophy, spinal muscular atrophy and several other neurological disorders. It was the initial discovery of this process of repetition of otherwise normal DNA sequences which led to scientists' ability to improve screening and diagnosis, and laid the foundation for research to overcome Fragile X and other "triplet repeat" syndromes.

Prader Willi Syndrome

Prader Willi Syndrome (PWS) is a disorder caused by a genetic defect on Chromosome 15, leading to mild to moderate mental retardation and severe eating disorder. Though most people with PWS have sufficient skills to lead normal lives in the community, they are usually unable to control their appetite and eating, and as a result are often placed in highly restrictive and costly treatment settings. Drs. Elizabeth Dykens and Robert Hodapp at the MRRC at UCLA have made significant contributions toward understanding the underlying psychopathology and motivational characteristics of individuals with PWS. The first major comprehensive study of PWS is currently underway at the Kennedy Center at Vanderbilt University sponsored by NICHD. Several candidate genes believed to be responsible for specific features of the syndrome have been identified. It has been discovered that 60 percent of people with PWS also display Obsessive Compulsive Disorder that amplifies the severity of their eating disorder. This important lead may assist in identifying the specific gene or shared in common between PWS, autism and Obsessive Compulsive Disorder, the latter condition affecting an estimated 6–7 million Americans. Understanding the metabolic defect in this syndrome and the cause of the severe eating disorder could have important implications for understanding a broader range of obesity and health related conditions relevant to 58 million overweight American adults.

LANGUAGE, COMMUNICATION, AND LEARNING IN DEVELOPMENTAL DISABILITIES

Under an NICHD sponsored program of excellence in autism research, a network of 10 research centers are exploring brain-language-genetic relationships among individuals with autism. Even among disabilities which are often considered ıless severeı, such as learning disabilities, difficulty with reading and communicating can create extreme disadvantage. Recent developments at the E.K. Shriver Center in Waltham, MA and at the University of Kansas MRRC in Lawrence, KS, have greatly improved our understanding of prerequisites to language development. Shriver Center scientists have demonstrated pre-reading techniques can be taught to people with severe mental retardation, which is a remarkable accomplishment. Other researchers have provided strategies for accelerating language acquisition in preschool children with developmental delays, including the work of Drs. Steve Warren and Paul Yoder at the Kennedy Center at Vanderbilt University. They have developed

techniques for jump-starting language growth of you ngsters pre-linguistically which appears to have lasting effects in early childhood. Work going on at other MRDDRCs using brain analysis methods have shed new light on linkages among basic communication processes, underlying brain mechanisms and intervention strategies. These developments include a greater appreciation for the development of early sensory, perceptual and memory skills and the manner by which they are critical to subsequent development of communication skills and learning. Another crit ical issue in future research is to better understand how the characteristics of individual children with disabilities or at risk for disabilities can be used to tailor make interventions to jump-start language development.

FAMILY AND OTHER FACTORS CONTRIBUTING TO RISK FOR, AND RESILIENCE AGAINST ADVERSE DEVELOPMENTAL OUTCOMES

Risk and resilience to adverse developmental outcomes is a major focus of the NICHD's research program. In order to target interventions to children at the highest risk (e.g. not all children growing up in poverty have poor developmental outcomes), and to develop the most cost effective preventative interventions, researchers at the Civitan Center at the University of Alabama at Birmingham have studied the nature of family, social and cultural risk and resilience factors that are predictive of children's developmental outcomes. Cultural differences in child rearing practices suggest that practices which may be problematic under one set of circumstances, can lead to positive developmental outcomes in another. Over the coming years, we recommend more attention be paid to precisely delineating these individual, family, community and cultural factors that contribute to resiliency or increase susceptibility to adverse developmental outcomes, and how we can translate that information into more effective early intervention procedures.

DESTRUCTIVE AND REPETITIVE BEHAVIOR

Fortunately, most people with mental retardation or related developmental disabilities do not have serious behavior problems. But aggression, property destruction and self injury are disproportionately related to developmental disabilities. The human suffering and economic cost associated with destructive behavior of people with developmental disabilities are staggering. Among people with certain disabilities, behavior problems are ubiquitous, e.g. Autism and ADHD. The co-occurrence of behavior problems and mental retardation leads family members, doctors, teachers and other caregivers to seek improved and more cost-effective treatments for unresolved problems. Researchers at the University of Kansas MRRC at Lawrence have examined the use of psychotropic medications to treat severe behavior problems of adults with mental retardation, and scientists at the University of California at Irvine, and Kennedy Center at Vanderbilt University have developed cost-effective medication treatments for self injury in autism and other developmental disabilities with a very high success rate.

Major advances have been made in the development of a newer generation of safer medications to manage some of these behavior problems. Regrettably there is very little published research regarding the effectiveness of these newer "atypical" neuroleptics, antidepressant and mood disorder medications in treating individuals with mental retardation and developmental disabilities. Far more emphasis needs to be placed on targeted initiatives to promote research on these important and timely topics. It is now apparent that even similar appearing destructive behavior exhibited by individuals with disabilities may have very different underlying causes, and correspondingly require different treatments. In the coming years, research on the sources of individual and group differences in responsiveness to treatments should be a major focus of these efforts.

SUMMARY AND RECOMMENDATIONS

As you can see Mr. Chairman and members of the Committee, the NICHD and the scientists it supports, have made significant contributions toward preventing disabilities and developing new treatments for problems associated with mental retardation and related developmental disabilities.

With your continued support in the areas indicated above, we believe the NICHD in partnership with scientists in the MRDDRCs and other research centers will continue to reduce the burden on families, schools, doctors and others with responsibility for the care, education and treatment of individuals with developmental disabilities.

We are grateful for your continued support and ask that you continue efforts to double the NIH funding by the year 2003 and appropriate, for fiscal year 2000, 15 percent increase to the NIH overall and fund the National Institute of Child Health

and Human Development at $915 million. This increase, also supported by the Friends of NICHD Coalition, will help us to continue our research into the causes and cures of mental retardation and developmental disabilities and, in turn, to better the lives of those living with such conditions.

PREPARED STATEMENT OF DONNA LEDDER MELTZER, CHAIRMAN, FRIENDS OF NICHD COALITION

Mr. Chairman and Members of the Committee: I am pleased to be able to submit to you this testimony on behalf of the Friends of the National Institute of Child Health and Human Development (NICHD), a coalition of nearly 100 organizations that support the extraordinary work of the National Institutes of Health with a special focus on the National Institute of Child Health and Human Development. Our coalition is now in its 13th year and includes in its membership scientists, health professionals, and advocates for the health and welfare of women, men, children, adolescents, families, and people with disabilities. Pursuant to clause 2(g)4 of House Rule XI, the coalition does not receive any federal funds.

As you know, the NICHD recently celebrated its 35th Anniversary and the Friends Coalition again thanks you for your support in serving as an honorary co-host of the Coalition's Scientific Exhibition and Reception held on June 3, 1998. This event featured presentations by 15 researchers or groups of researchers whose work is funded by the NICHD. We believe that this event gave us a chance to show you and your Committee where the appropriated dollars for NICHD are going and how wisely they are being used.

As the NICHD begins work in its 36th year, it can look back on a rich history and an impressive record of achievement, conducting and funding research on the prevention and treatment of many of the nation's most devastating health problems: infant mortality and low birthweight, unintended pregnancy, birth defects, mental retardation and other developmental disabilities, and pediatric AIDS. However, support is needed to continue progress. The Friends of NICHD Coalition respectfully requests that the NICHD be funded for fiscal year 2000 at $915 million and we concur with the Ad Hoc Group for Medical Research Funding that the NIH overall must receive a 15 percent increase to remain on track for doubled funding by 2003.

Anne Frank, in her famous diary said, "How lovely to think that no one need wait a moment. We can start now, start slowly, changing the world." I believe that this statement rings true for scientific research and its possibilities and hopes for the future. Scientific research is an investment over time. It begins slowly with the discovery of a gene, an atom, a chromosome and grows until it results in finding a cause or a cure for a devastating disease or disability. And, when a cure is discovered, it dramatically changes the world.

I am proud to be able to share with you today some of the ways in which NICHD has changed the world and, with continued strong congressional financial support, will keep changing the world.

HOW THE WORLD HAS CHANGED

Hemophilus influenzae type b meningitis, once feared as the leading cause of acquired mental retardation for our children, will not be seen again as it has been eliminated by vaccine technology developed by NICHD intramural scientists.

Mental retardation due to phenylketonuria (PKU), congenital hypothyroidism, jaundice, measles, and rubella will also be left behind as a relic of the past due to research discoveries that prevent these conditions.

Fear of maternal death in childbirth, that occurred in one percent of all pregnancies as we began the current century, has all but disappeared for American women as we begin the next century, due to better pregnancy management and control of hemorrhage and infection.

The potential for social isolation and mistreatment of persons with mental retardation and physical disabilities has greatly diminished because of NICHD research, which has improved ways to teach, manage behavior, increase mobility, and change public attitudes toward people with disabilities.

Infertility, which has left couples unable to have children of their own, now have access to a wide range of techniques to diagnose newly discovered causes of infertility, and to numerous treatment options to help them have their own children.

The prospect of having an infant die before its first birthday has been reduced by seventy percent since NICHD was founded. This is due primarily to new ways developed by the NICHD to treat or prevent respiratory distress syndrome and manage premature infants, and the Back to Sleep Campaign that has cut SIDS death by 50 percent in just five years.

And, gone are the days when a woman infected with AIDS could not protect her baby from the infection. NICHD and the National Institute of Allergy and Infectious Diseases (NIAID) have developed ways to reduce the rate of virus transmission from mother to infant from twenty-five percent to two percent.

HOW THE NICHD IS CONTINUING WORK TO CHANGE THE WORLD

Childhood Development and Degenerative Brain Disorders.—The NICHD has substantially increased its efforts to develop and apply noninvasive neuroimaging technology to better understand both the normal and atypical development of the developing brain and nervous system. NICHD currently supports eight major research sites that are carrying out both structural and functional neuroimaging with normal children and children with learning disabilities, dyslexia, and attention disorders. At three of these sites, functional neuroimaging studies are being conducted with children before, during, and after they receive intensive intervention for reading disabilities. These studies are the first of their kind, and will provide information about the functional plasticity of the developing brain, and changes that occur in the brain as cognition, language, and reading improve.

In the NICHD/NIDCD Network on the Neurobiology and Genetics of Autism, ten Collaborative Programs of Excellence in Autism (CPEAs) are studying brain structure and function in patients with autism and related disorders. Functional brain imaging is being used in eight projects to see how persons with autism process sensory input such as sound, vision, and touch. Structural imaging studies in one project are assessing changing in brain mass throughout development to determine if there is an ongoing degenerative process that could be potentially treatable. In an additional five projects, structural and functional imaging is being used to study brain development and function in disorders such as Williams' Syndrome, Lesch-Nyhan disease (a self-mutilating disorder), Rett Syndrome, intracranial hemorrhages and preterm babies and fetal brain injury in children. Data from these imaging studies are being combined with neuropathological studies using tissue from NICHD-funded brain banks that specialize in pediatric disorders to yield unique insight into childhood brain disorders.

A significant need in the development of a pediatric neuroimaging research program is the establishment of a normative data base for both structural and functional neuroimaging applications with children. Within this context, the NICHD, NIMH, and NINDS are collaborating on two major contractual research programs. One is to obtain data on normal structural (anatomic) brain development in children from birth to 18-years-of-age, and a second program is to obtain data on normal neurophysiological (functional) development in children. It is anticipated that several Pediatric Structural Neuroimaging Study Centers will be in operation by fiscal year 2000, with Pediatric Functional Neuroimaging Study Centers on line by fiscal year 2001.

Infertility and Contraceptive Research.—For more than three decades, NICHD has been one of the world's leaders in the research and development of new contraceptive drugs and devices. Rather than diminishing, its role has become even more important in recent times. Women and their partners who seek to avoid unintended pregnancy, and increasingly, sexually transmitted diseases and HIV/AIDS, need methods which are safe, effective, easy to use and inexpensive. For a variety of reasons, the private sector has not stepped forward to meet these needs. NICHD must have adequate funding to continue to make its critical contribution in this area, particularly in its efforts to develop a microbicidal preparation that would offer protection against both STDs and pregnancy.

The National Longitudinal Study of Adolescent Health (ADD Health).—NICHD is the lead agency on one of the most exciting and informative studies ever developed on adolescent behavior, know as ADD Health. Authorized by Congress in 1993, the study has followed a large group of adolescents over a period of several years to determine the causes of various risk taking behaviors that may eventually have a heavy impact on their overall health. Analysis of the findings have begun, so far yielding invaluable information on family and school networks' and communities' effects on the behavior of teenagers. With adequate funding, researchers funded by NICHD can take advantage of a one-time-only opportunity to learn about these young people once again as they reach young adulthood.

Fragile X.—Fragile X is the most common inherited cause of mental retardation and results from the failure of a single gene to produce a specific protein. Tremendous progress has been achieved in developing and characterizing animal models for Fragile X which have already provided insight into synaptic (nerve junction) abnormalities and the functional consequences. NICHD recently co-sponsored with FRAXA Research Foundation a special workshop of clinical and basic scientists from

the Fragile X field and related areas where research in the pathophysiological basis, screening and diagnosis of this disorder were discussed and treatment strategies and future research directions were formulated. The NICHD Pediatric Pharmacology Research Units (PPRUs) Network will expand its scope to include psychopharmacology clinical trials which could admit individuals with Fragile X in the PPRUs.

Learning Disabilities.—The federal government has recently focused a large effort to create a society of readers and adopted the largest budget ever for education expenditures. Yet, children and adults with learning disabilities (LD) still struggle to compete in school and in the workplace. In an effort to change the stigma attached to learning and reading disabilities, NICHD has also placed a high priority on learning disabilities research. Currently, the NICHD supports research on learning disabilities, reading development, reading disability, and reading instruction at 36 research sites located in 18 states and the District of Columbia. To date, NICHD-supported scientists have studied 34,501 children and adults, including 21,860 skilled readers and 12,641 disabled readers. In addition, over 3,000 children with learning disabilities in reading, mathematics, written language, and attention disorders have been enrolled in research studies. For these studies, over 2,500 research articles, books and chapters have been published and provide the scientific and educational communities with critical information relevant to early identification and intervention, prevention, prevalence and developmental course, as well as the development of remediation programs for older children, adolescents, and adults with reading and other learning disabilities. NICHD program scientists have presented reading research findings to the leadership in several states and have collaborated with states to develop early intervention and prevention programs for children who are at-risk for reading failure. Among these states are California, Connecticut, Illinois, Mississippi, New York, Pennsylvania, Vermont and Wisconsin. The NICHD has also recently increased its efforts to identify critical language and cognitive factors that are involved in the development of mathematics abilities in children.

Demographic Research.—Also integral to the scope of work at NICHD, is Demographic Research which provides objective, policy-relevant scientific information about our population trends. Most recently the NICHD has initiated research on poor families and neighborhoods, adolescent health, welfare-to-work transitions, and child care. The Institute's leadership in developing new data and research on fatherhood will help to fill a serious gap in our understanding of family formation, family strengths, the development and well-being of children.

Sudden Infant Death Syndrome (SIDS) Research.—Last year we were proud to report to you that through NICHD research and collaboration with the Back to Sleep Campaign, infant deaths due to SIDS has decreased by 50 percent. From its inception, the Back to Sleep campaign has focused on reaching parents and caretakers of all newborns with the goal of having 90 percent or more of healthy infants between one month and one year of age sleeping on their backs. However, data indicates that there is still a higher number of cases among minority families. Therefore, NICHD has initiated several new dissemination efforts as well as collaborative projects targeted to specific areas. One such project focuses on the Aberdeen Area and is a collaborative study between NICHD, the Indian Health Service, the CDC and the Aberdeen Area Tribal Chairman's Health Board. Investigations into the causes of, and risks for, the high rate of infant mortality among the Northern Plain Indians of the Aberdeen Area demonstrated high rates of cigarette smoking and alcohol use among pregnant women. Analyses are now focusing on the contributions of these risks to the number of SIDS deaths among the population.

The Chicago Infant Mortality Study, conducted in collaboration with the CDC in Chicago, Illinois, examines environmental, behavioral, and medical risk factors for sudden infant death in a high risk, predominantly African American, inner city community. These analyses are focusing on the hazards in the sleep environment that should be targeted in public health campaigns.

In addition to these studies and others, NICHD is also engaging in research on the efficacy of a monitoring device that is designed to detect episodes of breathing and heart dysfunction while an infant is sleeping. It is hoped that all of these collaborative efforts and studies will help NICHD reach its goal of 90 percent in the very near future.

Women's Reproductive Health Initiatives.—As we approach the 21st century, NICHD's research will lead to additional advancements to protect and improve the health of women throughout their lifetime. Women's health research has implications in clinical practice, disease prevention, health promotion, and medical education. NICHD's research efforts to date have proven that the proper health management of women of childbearing age leads to the delivery of healthier infants and improvements in the health of women throughout their life-span. With increased

support, NICHD can target additional areas of study, such as: intensified research in women's health throughout the life-span including women in the perimenopausal and postmenopausal years who have specific health problems and concerns; increased research in obstetrics and gynecology including funding support for new Women's Reproductive Health Research Career Development Centers to provide OBGYN training to assist them in pursuing research careers; and finding answers and solutions for preterm labor which still accounts for approximately 75 percent of newborn deaths that are not related to birth defects and leads to many long-term health complications for women.

Behavioral and Social Sciences.—We all worry about the environment—what we and our children breath, drink, eat and are otherwise subjected to in our daily life on planet Earth. NICHD is concerned too and worries that a decaying urban environment can have enormous implications on human growth and development. The NICHD has developed an initiative titled, "The Science and Ecology of Early Development" that is designed to better understand the effects of poverty and behavioral, social, emotional, biological, neurobiological and genetic factors in early childhood development. In addition, the NICHD is currently supporting functional neuroimaging studies that provide a window to brain development and change in children reared in poverty as they receive early reading and language interventions. The information derived from these studies will help us understand the plasticity of the brain during different times in development, and the specific types of behavioral interventions that can improve neural functioning.

Mr. Chairman, as you can see, NICHD has been working overtime to advance on the vast array (and we've only highlighted a few!) of research that is needed. The past 36 years has been a watershed of knowledge and progress. But there remains much work to do. We commend you for your steadfast commitment to medical research and we urge you and your committee to take any and all actions necessary to continue progress toward doubling the NIH's funding by 2003. In addition, we urge you to increase the funding for NICHD specifically, an Institute with an impressive record and huge workload but one that has lagged behind other Institutes in its funding levels. Again we thank you, Mr. Chairman and the Committee for your support and thank you for this opportunity to share comments.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF BLOOD BANKS

The American Association of Blood Banks (AABB) is pleased to offer this statement in support of increased funding for the National Institutes of Health (NIH), the National Heart Lung and Blood Institute (NHLBI) and transfusion medicine research. The AABB thanks Congress for recognizing the immense value of NIH and federal biomedical research efforts. We urge Congress to continue on the path toward improving the nation's health by supporting a 15 percent increase in NIH funding for fiscal year 2000. Last year, following the leadership of Chairman Specter and others, Members of Congress acknowledged the importance of doubling the NIH budget over five years. A 15 percent increase, which is supported by the Ad Hoc Group for Biomedical Research Funding, is necessary if we are to reach this common goal.

THE AMERICAN ASSOCIATION OF BLOOD BANKS

AABB is the professional society for over 9,000 individuals involved in blood banking and transfusion medicine and represents approximately 2,200 institutional members, including community and Red Cross blood collection centers, hospital-based blood banks and transfusion services as they collect, process, distribute and transfuse blood and blood components. AABB members are responsible for virtually all of the blood collected and more than 80 percent of the blood transfused in this country. For over 50 years, the AABB's highest priority has been to maintain and enhance the safety of the nation's blood supply.

The AABB has also been a strong supporter of transfusion medicine research. A program of the AABB founded in 1983, the National Blood Foundation (NBF), supports patient and donor care through scientific research, operational studies and public education. Recognizing the need for innovative research, the NBF has awarded over $2.2 million in grants to scientific investigators in the blood sciences. Committed to enhanced research in transfusion medicine, the AABB firmly believes that additional federal support for research is vital to the nation's efforts to ensure a safe and adequate blood supply.

RESEARCH LEADS TO SAFER BLOOD SUPPLY AND IMPROVEMENTS IN LIFESAVING TRANSFUSION MEDICINE

Today, the nation's blood supply is safer than it has ever been. Each year, over 23 million units of blood components are transfused into approximately four million individuals. Transfusion medicine benefits a diverse group of millions of Americans, including individuals battling life-threatening diseases such as cancer and heart and lung disease, newborns requiring intensive care, accident and burn victims, and patients requiring surgery or transplants. Improvements in blood safety and transfusion medicine are a direct result of both public and private support for biomedical research in this critical area of medicine.

With continued and enhanced federal support for research and the NHLBI, transfusion medicine promises new, life-saving blood-related therapies as well as an even safer blood supply in the United States. We have outlined below certain research areas that offer particular promise in improving the health of individual Americans as well as the overall safety of the nation's blood supply. The AABB strongly encourages Congress and the NIH to support such research initiatives.

IMPROVED DONOR SCREENING AND TESTING TO PREVENT TRANSFUSION-TRANSMITTED INFECTIONS

The estimated risk of transfusion-transmitted HIV is now only one in 676,000 transfusions and only one in 103,000 transfusions for transfusion-transmitted hepatitis C virus (HCV). Despite the great progress that has been made in the selection of donors who are at low risk for disease transmission and the use of and improvements to an extensive battery of tests to eliminate infected donors, the prevention of HIV and other transfusion-transmitted infections remains a top priority of transfusion medicine researchers and all recipients of blood. The AABB urges the NIH to continue research into the development of enhanced infectious disease tests and donor screening methods to improve further blood safety. The Association also encourages NHLBI's continued surveillance of emerging infectious diseases

Donor screening

Donor questioning is a critical step in maintaining a safe blood supply. Over the years, the questions presented to blood donors have been continuously revised, and today, questioning more directly addresses issues such as travel to regions with endemic disease patterns and sexual and drug use patterns. As a result of improved donor screening and education efforts, the volunteer donor pool is now primarily comprised of persons with lower infectious disease risks.

However, additional research is needed to refine and validate donor screening protocols. A report of the NHLBI funded Retrovirus Epidemiology Donor Study published in 1997 concludes that, although a stringent donor screening system is in place, a small percentage of donors with risk for infectious disease continue to donate blood. Although sophisticated laboratory testing that is conducted on all donated blood would have detected virtually all HIV or other infections among most of these donors, it is disturbing that this link in the blood safety process appears to be incomplete. The AABB urges the NHLBI to fund research to develop more effective donor screening methods to emphasize the potential adverse impact on patient health of providing misleading or inaccurate information during the blood donation process.

Moreover, as noted during a recent meeting of the Food and Drug Administration (FDA) Blood Products Advisory Committee, behavioral research is needed to ensure optimum donor comprehension of screening questionnaires and, whenever possible, to simplify the questionnaires so as not to discourage individuals from donating. The AABB recommends NHLBI support research to improve upon donor screening methods.

Blood screening tests

Blood screening tests have improved dramatically, allowing for more accurate and timely detection of several infectious diseases, including AIDS and hepatitis C. These tests are, however, not perfect. There is a "window period" of time between when a donor is infected with a viral disease and the time when the test can detect the infection. With research advances and new, improved tests, the window periods for HIV and HCV have decreased notably. However, until very recently, decreases in the window period have been limited by the fact that blood screening tests have detected the presence of the antibodies produced in response to the targeted virus, rather than the virus itself.

To improve infectious disease tests by further shortening the window periods, the NHLBI has funded valuable research into the use of nucleic acid amplification tech-

nology (NAT) for the detection of the genetic material of viruses that cause AIDS and hepatitis C. As a result of this and other research, new NAT testing (currently under INDs from the FDA) is being introduced with the promise of decreasing the window period for HIV by roughly 10 days and, even more substantially, for HCV by roughly 10 to 30 days. The AABB recommends that Congress and NHLBI support additional research into further improved blood screening tests to detect blood-transmitted diseases.

PERIPHERAL BLOOD STEM CELLS

Research has led to the discovery of additional blood-related therapies beyond the more traditional transfusion of whole blood or components. Some of the most exciting medical advances in recent years have involved the use of hematopoietic progenitor stem cells (HPCs). HPCs are harvested from peripheral blood using a process known as apheresis. A single HPC can produce red blood cells that carry oxygen, white blood cells that fight disease and platelets that stop bleeding. Transplants of these stem cells are increasingly replacing bone marrow transplants for reconstituting bone marrow in chemotherapy patients. Because of their ability to multiply into many different types of blood cells, HPCs may also become the ultimate vehicle for curing diseases through gene therapy.

In addition to peripheral blood, another source of HPCs is the blood remaining in the placenta and umbilical cord after delivery of newborn babies. The AABB has strongly supported NHLBI's efforts in funding a five-year multi-center study of the transplantation of stem cells collected from cord blood. To establish the necessary infrastructure for this research, the Institute established a network of umbilical cord blood banks and transplant centers. This research has already begun to lead to new findings regarding the clinical efficacy of cord blood stem and progenitor cell transplants.

Recently, the NHLBI and National Cancer Institute have discussed plans to establish a national network of clinical trials studying HPC transplants. The AABB believes increased national support for this research, including issues relating to the collection and processing of HPCs, is warranted. A variety of both biological and technical issues surrounding HPC transplants require continued investigation. These include proper immunologic and functional characterization of the stem cell, investigation of methods of stimulating stem cell production in normal donors, and optimum methods for the collection, processing and storage of HPCs. The AABB supports basic and applied HPC research.

IMMUNOLOGY OF TRANSFUSION

Even absent transmissible diseases, because transfused blood components are recognized as foreign substance by the human body, blood transfusion can produce adverse changes in the body's natural immune defenses. Changes include the potential for decreasing the natural defenses of blood recipients in their fight against bacterial infection and preventing or decreasing the incidence of cancer recurrence. Fundamental basic research by transfusion medicine specialists is needed to gain vital knowledge on how to combat this adverse aspect of blood transfusion. Transfusion researchers are also poised to make great strides in understanding the molecular biology and function of blood cell antigens.

Preliminary research suggests that when standard blood components are modified in certain ways, such as by exposure to gamma irradiation or by removal of donor leukocytes or donor plasma, the immune altering effect of transfusion may disappear. The role of cytokines as mediators of transfusion-associated immune modulation may represent a possible avenue of research. The AABB urges the Subcommittee to support research to investigate transfusion-related immune responses.

THE ROLE OF BIOLOGICAL RESPONSE MODIFIERS IN TRANSFUSION REACTIONS

Clinical and experimental studies have identified several substances released by human cells which play a significant role in altering a patient's response to transfusion. These adverse responses (known as transfusion reactions) range from fever, hives, shaking, and chills to sever allergic reactions, shock and even death. Transfusion medicine researchers now know far more about these families of biological response modifiers, which include histamine, complement, cytokines, bradykinin and other biologically active molecules. Studies of the role of these mediators in adverse reactions to transfusion, and research into how to modify and control these response modifiers is needed. Basic and clinical research in these areas will provide a fruitful avenue for improving the safety of blood transfusion for adult and infant transfusion recipients alike.

CENTERS OF EXCELLENCE FOR TRANSFUSION MEDICINE RESEARCH AND TRAINING

Improving transfusion medicine research training and its clinical research infrastructure is vital to furthering transfusion medicine research productivity. Such an infrastructure is currently nonexistent. Medical students need to be encouraged and provided needed training to enter transfusion medicine. In addition, better coordinated, national clinical trials could prove invaluable in improving patient care and increasing blood donations. Accordingly, the AABB strongly supports development of a system of linked Centers of Excellence for transfusion Research and Training. Such centers could provide the critical mass of resources needed to accomplish NIH/NHLBI sponsored research initiatives in the transfusion medicine areas outlined above.

HEALTH ISSUES

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

The American Association of Nurse Anesthetists is the professional association that represents over 27,000 certified registered nurse anesthetists (CRNAs) in the United States. AANA appreciates the opportunity to provide our experience regarding federal funding for nurse anesthesia educational programs under Title VIII, the Nurse Education Act (NEA). Many members of our association have benefited greatly over the years from the Title VIII programs, which in turn has benefited the health care system by assisting in the maintenance of a stable supply and adequate number of anesthesia providers.

BACKGROUND INFORMATION ABOUT CRNAS

In the administration of anesthesia, CRNAs perform many of the same functions as physician anesthetists (anesthesiologists) and work in every setting in which anesthesia is delivered including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers, health maintenance organizations, and the offices of dentists, podiatrists, ophthalmologists, and plastic surgeons. Today, CRNAs administer more than 65 percent of the anesthetics given to patients each year in the United States. CRNAs are the sole anesthesia provider in at least 65 percent of rural hospitals, which translates into anesthesia services for millions of rural Americans. CRNAs are also front line anesthesia providers in underserved urban areas.

CRNAs have been a part of every type of surgical team since the advent of anesthesia in the 1800s, and until the 1920s, anesthesia was almost exclusively administered by nurses. In addition, nurse anesthetists have been the principal anesthesia provider in combat areas in every war the United States has been engaged in since World War I. Though CRNAs are not medical doctors, no studies have ever found any difference between CRNAs and anesthesiologists in the quality of care provided, which is the reason no federal or state licensing statute requires that CRNAs be supervised by an anesthesiologist. Anesthesia outcomes are affected by such factors as the provider's vigilance rather than the title of the provider—CRNA or an anesthesiologist.

The most substantial difference between CRNAs and anesthesiologists is that prior to anesthesia education, anesthesiologists receive medical education while CRNAs receive a nursing education. However, the anesthesia education offered is very similar for both providers and both professionals are educated to perform the same clinical anesthesia services: (1) preanesthetic preparation and evaluation; (2) anesthesia induction, maintenance and emergence; (3) postanesthesia care; and (4) peri-anesthetic and clinical support functions, such as resuscitation services, acute and chronic pain management, respiratory care, and the establishment of arterial lines.

There are currently 82 accredited nurse anesthesia education programs in the United States, all of which are required to offer a master's degree.

THE HEALTH PROFESSIONALS SCHOLARSHIP PROGRAM

Are there enough providers to meet the goals?

The Health Professionals Scholarship program was created to address certain needs of the population, including increased access to primary care, increased access in rural and underserved areas, and improved distribution of providers. But before we can begin to focus on the goals of the Health Professionals Scholarship Program, there must be assurances that our programs are producing enough graduates to serve the population as a whole.

The overall number of primary care physicians providing patient care rose by 75 percent between 1975 and 1990; yet, the population as a whole rose by only 17 percent. The result has been a physician surplus. Yet the same is not true for other health care professions. The surplus of physicians does not necessarily translate to a surplus of all providers. Nurse anesthesia programs across the country have stabilized, not increased, in the number of graduates produced each year, averaging approximately 900–1000 new nurse anesthetists entering practice annually.

Data have shown that a continued supply of 1000 graduates per year will provide the country with a stable, adequate source of anesthesia providers. Previous research by Michael Fallacaro, CRNA, DNS, Professor and Chair of the Nurse Anesthesia Department, School of Allied Health Sciences at Virginia Commonwealth University, established that the current ratio of approximately 8.5 CRNAs per 100,000 population is adequately meeting societal demands. In addition, his research showed that adding 1000 new nurse anesthetist graduates into the system each year through 2020 would ultimately result in a similar ratio of 8.5 to 9.6 CRNAs per 100,000 population, depending on the average retirement age. Therefore, by continuing the trend of graduating approximately 1000 students per year, nurse anesthesia programs appear to be producing not a surplus of providers, but an adequate number to meet societal needs.

In order to maintain this number of graduates, CRNA students need continued federal support. Nurse anesthesia programs require a rigorous course of study that does not allow students the opportunity to work outside their educational program. Nurse anesthesia programs are virtually all full-time, with part-time study a rare occurrence. Therefore, nurse anesthesia students rely heavily on federal funding to assist them in meeting financial obligations during their study. Without this assistance, the number of nurse anesthesia graduates would surely decline. A decline in the number of nurse anesthetists would then result in a decline in the accessibility to services, primarily in rural areas that depend on non-MD providers for the majority of their care.

What are the goals of the Health Professionals Scholarship Program, and how does an investment in CRNA education help to achieve them?

Title VIII has supported the education of our nation's nurses since the 1960s. It provides programs for direct student assistance as well as grants to institutions for expansion or maintenance of education. While initially the programs focused on increasing enrollments, in the mid-1970s they began to shift toward increasing the number of primary care providers and increasing the number of professionals serving in rural or underserved areas.

The current authorization, the Health Professions Education Partnerships Act of 1998, establishes preferences and goals for the program to achieve. Specifically there is an interest by Congress to improve the access to and distribution of providers in rural and underserved areas. The investment in the education of nurse anesthetists would assist in achieving this goal.

CRNAs are the sole providers of anesthesia in at least 65 percent of rural hospitals. Anesthesia provided by CRNAs allows these rural facilities to provide obstetrical, surgical, and trauma stabilization that would otherwise not be possible for millions of Americans in rural areas. Continued federal support of Title VIII programs will ensure a stable supply of CRNAs to rural facilities all across the country. In addition, many nurse anesthesia programs are located in medically underserved urban areas and produce graduates that eventually enter practice after graduation in these same communities.

Continued research by Fallacaro has shown that urban areas still retain far greater percentages of anesthesia providers. The data vary widely from state to state depending on its makeup; however, the conclusions are clear. The national average for CRNAs is 81.3 percent practice in urban areas, compared to 18.7 percent in non-urban areas. For anesthesiologists the numbers show an even more significant difference, with a mere 7.8 percent residing in rural areas. Clearly this shows that while urban areas have more anesthesia providers, the rural areas are predominantly served by CRNAs.

It is likely that the problem of distribution will only get worse, as an aging CRNA population is concentrated more in non-urban areas than in urban. Looking at the CRNA population as a whole, approximately 19 percent provide services in non-urban areas. Focusing solely on the CRNA population aged 55 and older, approximately 29 percent provide services in non-urban areas. This indicates that a disproportionate number of CRNAs in rural areas are aged 55 or older. As these CRNAs retire, it remains unclear what will happen to anesthesia services in those areas without continued incentives such as the Health Professionals Scholarship Program.

Access to anesthesia services is critical to the health of patients in rural and underserved areas. The Health Professionals Scholarship Program, and specifically the investment in the Nursing Workforce Development section, will help maintain a stable supply of anesthesia providers for these areas.

REPORT LANGUAGE REGARDING THE HCFA PROPOSED RULE ON SUPERVISION

As the committee is aware, the conference report to the fiscal year 1999 Omnibus Appropriations bill contained language dealing with nurse anesthetists. Specifically, there was language which referenced a proposed rule issued by the Health Care Financing Administration (HCFA) that deferred to state law on the issue of physician supervision:

"The conference agreement recommends the Secretary base retaining or changing the current requirement of physician supervision of anesthesia services in Medicare on scientifically valid outcomes data. Concern has been expressed regarding HCFA's proposed elimination of this requirement which has been in effect since the inception of the Medicare program. The conference agreement further suggests that the Secretary request the Agency for Health Care Policy and Research to work with HCFA in a design and implementation of an outcome approach that would examine, utilizing existing Medicare operating room data, mortality and adverse outcome rates by different anesthesia providers, adjusted to patient acuity, and other relevant scientific variables. This methodology should be developed after consultation with the relevant national professional organizations. Nothing in this report shall be construed as encouraging, discouraging, or delaying HCFA from removing or retaining the current physician supervision requirement." (Congressional Record, October 19, 1998)

Similar language also appeared in the Senate Labor-HHS Subcommittee report. It is our understanding that the final language in both bills was deliberately crafted to be very flexible—flexible enough that HCFA and the Department of HHS could move forward with a final rule removing the supervision requirement without delay. However, we believe that this report language has led to confusion and further delay by HCFA.

This confusion has come despite the fact that the statement of the managers did not mandate, as a matter of law, any further studies by HCFA on this issue, nor that HCFA should be impeded from moving forward with issuing a final rule regarding the physician supervision issue. The AANA would appreciate any assistance the committee could provide in order to resolve this confusion.

As you may know, the current supervision requirement restricts the ability of states to determine whether physician supervision of nurse anesthetists is necessary, does not improve the quality of care, and may inhibit access to services in rural areas. Even taking into account the hospital statutes and regulations, there are still nineteen states that do not require supervision of CRNAs. In a September 2, 1998 article in JAMA, Cooper, Henderson, and Dietrich concluded that eighteen states permit CRNAs to practice "independently." (Cooper, Richard A., Henderson, Tim, Dietrich, Craig L., "Roles of Non-Physician Clinicians as Autonomous Providers of Patient Care." JAMA. 1998; 280:795–802 at Page 797, Table Two.) The AANA believes that supervision requirements do not improve the quality of care. Proponents of mandated supervision argue that it increases quality of care, but cite no evidence to support this proposition. All the evidence to date shows that the quality of care that nurse anesthetists provide is superb, regardless of whether nurse anesthetists are physician-supervised. In addition, the current federal requirement has acted as a disincentive for CRNAs to be utilized. Some surgeons have been dissuaded from working with CRNAs, believing they may be subjecting themselves to liability for "supervising" the CRNA. This is despite the fact that the principles governing liability of a surgeon when working with a CRNA are the same as those governing liability working with an anesthesiologist. Because CRNAs are the sole anesthesia provider in 65 percent of rural hospitals, surgeon concerns about liability could decrease access to surgical and anesthesia services in rural areas.

Let me state why this issue is important for this subcommittee. We are very grateful for the $2.7 million which the Appropriations Committee has provided annually in recent years for nurse traineeships and new program start-ups. This funding has been critical to ensure the continued education of nurse anesthetists throughout the years. However, you should know that your investment in the education of nurse anesthetists and their profession is impeded by this outmoded federal supervision requirement. This outdated HCFA regulation limits the ability of health care institutions to fully utilize the services of nurse anesthetists. Requiring physician supervision essentially discourages the use of CRNAs as anesthesia providers when facilities and surgeons can use another provider who does not to be su-

pervised according to federal regulations. Given the fact that Medicare reimburses CRNAs, federal funds help train them, and the military sends them into combat situations, it is clear the federal government specifically recognizes the value of nurse anesthetists. If you continue to want CRNAs to fill the ever-growing unfulfilled need in rural and underserved urban areas, as your funds assist us in doing, your assistance in removing this antiquated supervision law could be quite helpful.

In conclusion, the AANA is opposed to any effort that would delay or stop HCFA from moving forward and issuing a final rule on this issue. Congressmen Weldon (R-FL) and Green (D-TX) have introduced legislation, H.R. 632, that would force HCFA to conduct an outcomes based study which would constitute an extensive and costly delay for HCFA in issuing a final rule removing the supervision requirement. There have been numerous studies on this issue already, and another study would be a waste of money and time. To be precise, the Centers for Disease Control (CDC) chose not to embark on a new multi-million dollar study regarding anesthesia outcomes in 1990. Following a review of anesthesia data, the CDC concluded that morbidity and mortality in anesthesia were too low to warrant the study. H.R. 804, introduced by Reps. Jim Nussle (R-IA) and Bill Coyne (D-PA), essentially repeals the federal supervision requirement and lets the states make their own decision on this issue. We invite your support for that proposal and hope, that while it has been referred to another committee of jurisdiction, that you will favorably consider its merits, particularly in the context of anything which might be done in the appropriations process that addresses this issue.

The AANA looks forward to working with this committee, in whatever way that may be appropriate, to seek the issuance of a final rule that defers to state law on the issue of physician supervision.

RECOMMENDATIONS FOR FISCAL YEAR 2000

The nurse anesthesia community would appreciate and certainly utilize a substantial increase in funding, but recognizing the budgetary constraints faced by this Committee we would recommend continued federal funding for the Health Professionals Scholarship Program at the level of $316 million, which is a 4 percent increase over the fiscal year 1999 level. Included within the Health Professionals Scholarship Program, we are requesting that a minimum of $67.8 million be specifically designated for the Nursing Workforce Development section, which would allow for a minimum of $2.761 million for nurse anesthesia education.

In addition, AANA is hopeful that the Subcommittee, and Congress, will take another look at the issues surrounding the HCFA proposed rule that defers to state law on the issue of physician supervision of nurse anesthetists. The language included in the conference report to the Omnibus Reconciliation Bill for fiscal year 1999 has led to confusion and delay, and needs further clarification.

Thank you for your consideration of our concerns. If you need further information, please contact David E. Hebert, AANA Director of Federal Government Affairs at 202/484–8400.

PREPARED STATEMENT OF THE JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW

The Judge David L. Bazelon Center for Mental Health Law praises Chairmen Arlen Specter and Members of the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education for holding hearings to explore the long-standing problems regarding the use of restraints and seclusion in psychiatric facilities. The use of restraints and seclusion have led to trauma, injury and death for many of our most vulnerable children and adults in these settings across the country.

The Bazelon Center commends Senator's Joseph Lieberman and Christopher Dodd and Representatives Diana DeGette, Rosa DeLauro and Pete Stark for introducing legislation in both the Senate and the House to establish national standards for the use of physical and chemical restraints and seclusion. These long overdue standards would only allow the use in emergency situations for the immediate physical safety of the patient or others and only upon the written order of a physician. Although the bills vary in the protections they provide, all are positive steps toward creating procedural and substantive safeguards and reporting requirements governing the use of restraints and seclusion.

The Bazelon Center, through precedent-setting litigation, public policy advocacy and technical support to lawyers and other advocates, works to define and uphold the rights of children and adults with mental disorders who rely primarily on pubic

services. It is because of this mission that we raise our concern about the inappropriate, excessive, and, at times, deadly use of restraints and seclusion.

We have been concerned about this issue for sometime and continue to advocate for restraint-free facilities. Now, with the recent reports of deaths highlighted by the Hartford Courant newspaper articles we hope the significance of these tragedies will be fully recognized by legislators. It is critical that the Committee also explore the extensive trauma that consumers experience from the use of restraints and seclusion. We strongly advise the Committee to bring this issue to the awareness of all Members of Congress in hopes of building bipartisan support to enact strong protections. Now is the time to restore confidence in mental health treatment, free from harm.

Also with our support for the legislative proposals, we are also providing recommendations on the use of seclusion and restraints. In addition, we have outlined the Health Care Financing Administration's (HCFA) restraint and seclusion requirements addressed in the preamble to their proposed regulations on Hospital Conditions of Participation: Provider Agreements and Supplier Approval (Friday, December 19, 1997 Federal Register, Vol. 62, No.244). We feel the language of the preamble is very effective in seeking to reduce the use of restraints and seclusion and should be incorporated into the body of the rule.

Under the proposed HCFA rule:

—Seclusion or restraints may only be used to the extent authorized by the signed order of a physician. Written authorization must include the date and time of the order, and the reason for seclusion or restraint. For restraint, the order must include the type of restraints(s) and the number of restraint points.

—Each order for seclusion or restraints must be in writing, must be time-limited and specify start and end times. Implementing a time-limited order does not require applying the intervention for the entire period if the patient demonstrates a reduction or change in the behavior that led to being placed in the restraint or seclusion.

—A renewal order may be issued if the physician clinically assesses the patient face to face and determines that seclusion or restraint continues to be necessary to prevent injury to self or others, and there is no less restrictive method of preventing the injurious behavior.

—Orders for seclusion or restraint must never be written on a standing or as needed basis.

—Written orders for restraint and seclusion for adults must be valid for no more than six hours; written orders for restraint and seclusion for children and adolescents must be valid for no more than 2 hours.

—A patient in seclusion or restraint must be checked by a person trained in the use of restraints and seclusion at least every 15 minutes for comfort, body alignment, circulation, hydration, feeding, and toilet needs. A patient in seclusion or restraint must have vital signs checked a minimum of every 2 hours. Written documentation of checks must include, at a minimum, the name of the person doing the check, the date and time of the check, and the patient's condition.

We support the requirements described above and also recommend the following:

—All patients have the right to be free from seclusion and restraints.

—Restraint and seclusion are not treatment; they should only be allowed in emergencies which present imminent danger of significant physical injury to the patient or others, and only upon the written order of a physician.

—Restraint includes chemical as well as physical restraints.

—Seclusion and restraint should never be used in combination.

—Staff should be trained appropriately in the use of restraints and seclusion.

—All reports of death and serious injury should be made available to the state protection and advocacy system (P&A) within 2 hours so that they may investigate and discern which incidents require prosecution.

—Stiff penalties for failure to comply, including monetary fees and loss of federal funding.

—The patient's health care agent, or a family member, if involved, and the P&A should be notified within 2 hours when restraints and seclusion are used on the patient.

—Use of seclusion and restraints should be limited to the duration of the actual emergency.

—No physical restraint or seclusion method that causes pain or physical discomfort should be used.

—Hospitals should be required to collect and report data, including data on the use of seclusion and restraint and patient injuries and deaths.

—The facility should be required to check if the patient has an advance directive which covers psychiatric emergencies and should follow the patient's wishes as

expressed in the advance directive to the maximum feasible extent (for example, by using the medication of the patient's choice or avoiding certain types of restraints—which for patient who have been subject to abuse can be especially traumatizing).

—The patient's record should document the use of alternative approaches tried prior to the use of restraint or seclusion and/or the clinical rationale for why less restrictive measures were not appropriate.

—Placing of a patient in seclusion or restraint should by supervised by a medical staff.

—Seclusion and restraint shall not be used as punishment, coercion or for the convenience of staff.

Safeguarding and protecting vulnerable children, adults and elders in order to preserve, protect and uphold their dignity and human rights should be a priority of all Americans. We thank you for the opportunity to provide comments.

PREPARED STATEMENT OF WILLIAM W. MILLAR, PRESIDENT, AMERICAN PUBLIC TRANSIT ASSOCIATION

The American Public Transit Association (APTA) appreciates having this opportunity to testify on the fiscal year 2000 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

ABOUT APTA AND PUBLIC TRANSPORTATION

APTA is a nonprofit international organization that has been representing the transit industry for more than 100 years, since 1882. APTA's 1,200 member organizations serve the public interest by providing safe, efficient and economical transit service, and by working to ensure that those services and products support national energy, environmental, community, and economic goals. APTA member organizations include transit systems; design, construction and finance firms; product and service providers; academic institutions, and state associations and departments of transportation. More than ninety percent of the people who use transit in the U.S. are served by APTA member systems.

APTA submits this testimony before the Labor, Health and Human Services, and Education Subcommittee to make the point that public transportation can make an enormous difference in how effectively we, as a nation, provide people with access to jobs, health care, training, and other social services.

According to the Federal Transit Administration (FTA), 32 million senior citizens increasingly rely on transit as their driving ability decreases with age; 27 million people with disabilities depend on transit to maintain their independence; 37 million people living below the poverty level often cannot afford a car and use transit to reach their jobs. There are 56 million children under driving age, many of whom use transit to travel to and from school and for after-school activities.

OVERVIEW

Public transportation can and does play a critical role in providing services to millions of Americans. We ask that in developing the fiscal year 2000 Labor, Health and Human Services and Education bill, the Subcommittee consider three issues of particular importance to public transit. First, APTA requests that the Subcommittee direct the Department of Transportation (DOT) and the Department of Health and Human Services (DHHS) to complete joint coordination guidelines on human services transportation now being developed as soon as possible, following the example of the welfare-to-work guidelines. Secondly, we urge the Subcommittee to highlight the role that public transportation can play in providing cost-effective services for health and human service transportation activities. Last, APTA hopes the Subcommittee will urge health and human service providers to coordinate their transportation activities through the metropolitan transportation planning process.

DOT/DHHS COORDINATION IS CRITICAL

APTA strongly supports the initiatives of DOT and DHHS to improve coordination in the provision of transportation under social programs and health related services. According to the Department of Health and Human Services' Health Care Finance Administration's (HCFA) Non-Emergency Transportation Technical Advisory Group, it is extremely important to "Coordinate, coordinate, coordinate—(and) provide opportunities to coordinate, because it is in the best interest of community, state, health care, transportation industries and the state Medicaid agency to develop coordinated networks of transportation." We were pleased that such coordination was

called for in the fiscal year 1997 Transportation and Related Agencies and Labor, Health and Human Services Appropriations bills. APTA, the Coalition for Paratransit Solutions, and others have worked with Congress to encourage this collaboration. Both bills directed the Departments of Transportation and Health and Human Services to develop joint guidelines for coordination of DOT and DHHS transportation services, including joint identification of human service client transportation needs and the appropriate mix of transportation services to meet those needs; the expanded use of public transit services to deliver human services program transportation; and cost-sharing arrangements based on a uniform accounting system for DHHS program recipients transported by Americans with Disabilities Act paratransit systems.

On July 1, 1998, an ad-hoc advisory panel consisting of representatives from various organizations met to advise the DOT/DHHS Planning Committee on key considerations and challenges in developing guidelines for state and local coordinated planning related to human services transportation. The panel focused on several areas, including ways that the federal government can create more coordinated planning at the state and local levels. The DOT/DHHS Planning Committee was then scheduled to issue draft guidelines for public comment last fall. Although the Committee is said to have made progress on this initiative, we still await guidelines with the hope that they can influence how transportation dollars are spent in local communities. The joint guidelines will be invaluable in providing policy guidance for coordination activities by transportation agencies and human service providers at the local level. We urge this Subcommittee to direct DHHS and DOT to complete their joint coordination guidelines as soon as possible, and to consider the feasibility of involving other federal agencies, such as the Department of Labor, in the process.

PLANNING

Others in Congress also recognize the critical importance of coordination of these activities. We are pleased to note that the largest surface transportation infrastructure investment bill in our nation's history, the Transportation Equity Act for the 21st Century, (TEA 21) was enacted last summer. That legislation includes two provisions that deal specifically with the importance of coordination of transportation activities. First, the bill requires DOT to encourage metropolitan planning organizations in developing local transportation plans to coordinate the design and delivery of transportation services by all entities receiving federal funds for transportation purposes. Second, another provision requires the Comptroller General to conduct a study of Federal departments or agencies that receive financial assistance for non-emergency transportation services. APTA eagerly awaits the report required by that provision, which should contain recommendations for enhanced coordination between DOT and any Federal departments or agencies that provide such funding.

ACCESS TO HEALTH CARE—THE ADVANTAGE OF COORDINATED SERVICES

We continue to stress the importance of coordination of transit service with other government functions because of the great potential for saving tax dollars at all levels of government. According to the FTA, in four major programs—Medicare, Medicaid, Food Stamps, and Unemployment Compensation—each dollar invested in low-cost mobility services reduces the transportation cost of these programs by approximately 60 percent.

To lower health-care costs, non-driving outpatients may travel to health care by transit. The alternative may be expensive taxi or ambulance service. For example, across the nation transit vans carry thousands of people to and from dialysis treatment, saving as much as $200 to $400 per trip as compared to specialized medical transportation services.

In 1997, HCFA estimated that it was spending approximately $1.2 billion annually in non-emergency medical transportation. Since then, many state Medicaid offices have found waste, fraud and abuse within their transportation systems and have improved the delivery of transportation services at a reduced cost by coordinating with local public transit operators. In fact, 20 percent of the nation's Medicaid rides are now provided by public transit.

In 1994, the Office of Medical Assistance Programs in Oregon began a brokerage agreement with TRI-MET, the regional transit authority in Portland. At that time, the State estimated that the transit authority would provide approximately 37,000 rides per month to Medicaid recipients. Today, that total has grown to over 80,000, and 60 percent of all Medicaid trips in Portland are provided by bus or light rail. This partnership has increased access to health services while cutting the cost of non-emergency medical transportation by approximately 15 percent. Furthermore, State Medicaid officials have credited the increase in transit use with reducing prob-

lems associated with billing abuses. At the same time, TRI-MET has experienced a significant increase in revenue due to ridership growth and is considering similar arrangements to provide non-medical transportation as well.

The State of Vermont has proven that it is possible to provide cost-effective access to medical services in both rural and urban settings. The Vermont Public Transit Association has coordinated services with the state Medicaid agency since the inception of the program, providing virtually every non-emergency medical trip. Statewide, the cost of these trips is as low as $2.83, making Vermont's system one of the most economical in the nation.

Rhode Island is perhaps the best example of what can be accomplished when coordination is achieved among human service providers and public transit. In that state, 99 percent of all non-emergency medical travel is provided by the Rhode Island Public Transit Authority (RIPTA), which is under contract with five statewide managed care plans. The majority of the state's Medicaid recipients are enrolled in one of these plans. Remarkably, the state DHHS cost per ride is only about fifty cents.

The North Carolina Department of Transportation and the state Department of Health and Human Services have worked together since the 1970's in providing human service transportation to people with disabilities. The state recognizes the value of coordination and the desire to avoid institutionalized care whenever possible. North Carolina estimates that people who receive care while living at home can save themselves, their families and government agencies approximately $22,000 in annual costs by avoiding institutionalized care. Coordination between 55 human service transportation systems throughout the state makes this goal possible.

WELFARE TO WORK

Transit is also vital to the success of welfare reform. U.S. Secretary of Transportation Rodney Slater has said frequently that transportation is the "to" in welfare to work. The Department of Transportation clearly recognizes the need for coordination in this area, as evidenced by the joint guidance issued by DHHS and the Department of Labor (DOL) in concert with DOT on the use of Temporary Assistance for Needy Families (TANF), Welfare to Work, and Job Access Grants for transportation purposes. These guidelines encourage states to take advantage of existing resources to develop integrated services addressing the challenge of moving people from welfare to work.

In a similar vein, and in response to a request by FTA Administrator Gordon Linton, APTA's Executive Committee created the "Access to Jobs Task Force" to assess and coordinate activities concerning welfare-to-work issues. The Task Force encourages transit systems and businesses to hire welfare recipients and highlights the positive role that transit can play in making welfare-to-work a success. It also serves as a means to share information on successful programs with APTA members and encourages coordination of activities between transportation providers, health and human service agencies, and private firms.

The Access to Jobs Task Force conducted a Welfare-to-Work Survey in early 1998. More than 200 organizations participated in the survey, including 180 transportation providers and 38 businesses and other organizations that do not operate transportation service. Transportation providers furnished descriptions of new services that included supplemental work trip service programs, reverse commute programs, special transportation services programs, and vanpool programs. The "Welfare-to-Work Survey Summary Report," published in October 1998, concluded that coordination and cooperation among welfare and employment agencies, social service agencies, metropolitan planning organizations, private transportation service providers, neighborhood organizations and transit systems is essential for successful programs. The survey also noted that the effectiveness of transportation solutions depends on:

—Building on the services a transit agency already provides in order to ensure that existing service is fully utilized for welfare-to-work travel;
—Educating welfare caseworkers and job counselors on the availability of transit options so that they can direct their clients;
—The availability of funding; and
—New services, including new routes to employment locations outside the existing service area; more direct service to reduce long trip times; service later at night and earlier in the morning to meet extended hours of many entry level jobs; and increased service in the opposite direction of existing peak service.

Public transportation is responding to the challenge. The nation's public transit systems already provide access to jobs for millions of commuters, and are responding in new and innovative ways to provide job access for welfare recipients. Some

94 percent of welfare recipients who must move into the workforce do not own cars and must rely on public transportation to get to work. And while 60 percent of welfare recipients live in central cities, the majority of new jobs are in the suburbs. Transit operators are working to meet these needs by providing special reverse commute and suburb-to-suburb bus, rail and van services to match center city residents with suburban jobs.

For example, Chicago area transit operators Pace, the Chicago Transit Authority (CTA) and Metra have developed special reverse commuting programs. Let me highlight some successful welfare-to-work programs in the Chicago area.

—For several years, Pace has been working with United Airlines, United Parcel Service, Marriott, Avon and other major employers to design routes to get former welfare recipients to suburban locations. Pace was able to expand its services with assistance of funding from the Illinois Department of Human Services and a grant provided by the federal government under the Congestion Mitigation/Air Quality Improvement Program.

—Vans used in shuttle operations have recently been provided to employment training agencies for the transportation of job seekers and recent hires to entry-level job sites. Pairing job coaching with volunteer chauffeur responsibilities, these organizations have strengthened the relationships between agency staff and clients while efficiently using available human resources to provide a broad range of services. In a concept extension, a "homeless-to-work" shuttle application has been implemented in suburban McHenry County.

In addition to these innovative programs, the Regional Transportation Authority (RTA) and the Illinois Department of Human Services have partnered to develop a proposed Transportation Information Clearinghouse. In another case, the majority of a $3 million grant from the Department of Labor to the City of Chicago is being used to defer transit costs for eligible TANF recipients who locate jobs during their first six months of employment. Additionally, RTA and CTA will be conducting training for caseworkers from the Illinois Department of Human Services to insure that they are fully aware of the scope of public transit services, as well as how to use maps, fare cards, and other resources of the system.

AC Transit in the San Francisco Bay Area initiated a welfare-to-work pilot program in Richmond, California, by extending bus service from 7:00 p.m. to 1:30 a.m., seven days a week. Forty-five percent of the households served by that agency have no automobile. Although not profitable to the transit agency, this heavily subsidized program has proven to be very successful in providing people access to work.

Finally, the New York Metropolitan Transportation Authority's (MTA) Metro-North Railroad, Long Island Railroad (LIRR), and Long Island Bus have all pursued the reverse commute market through the addition of reverse peak service well before the advent of the welfare-to-work effort, carrying a total of 49,000 reverse commuters daily. LIRR and Long Island Bus have developed two reverse commute services involving distributor buses from LIRR stations. In cooperation with Westchester County DOT, local transit operators, and employers, Metro-North is providing bus services to corporate work sites where no previous service existed. Furthermore, MTA has helped to service the reverse commute market by lowering fares for intermediate travel (trips not originating or terminating at Grand Central Terminal). MTA also introduced unlimited-ride bus and subway Metro Card passes last summer. The 7-day pass is ideally suited to welfare-to-work passengers, since they are likely to make several trips each day to day care, training programs, and of course to work.

THE AMERICANS WITH DISABILITIES ACT

Another national priority in which public transportation plays a key role is implementation of the Americans with Disabilities Act (ADA). The ADA requires that transit operators offer paratransit service, as well as accessible fixed-route service, to persons with disabilities. The demand for ADA paratransit service has continued to grow, and complimentary paratransit service will still be needed even with fully accessible fixed-route service. APTA member organizations have worked aggressively to meet the important ADA accessibility goals. Virtually all fixed-route bus service and much of the nations' urban rail service is accessible. Transit agencies across the nation have submitted final plans to insure that they can meet the transportation needs of every person with a disability that cannot use fixed-route service.

We cannot, however, meet these growing demands from our traditional funding sources alone, and need the cooperation of health and human service providers at all levels of government—federal, state and local. With more than 95 million trips provided on demand responsive public transit in 1998, ADA capital and operating costs are estimated to be $1.4 billion annually. Accordingly, APTA urges this Sub-

committee to continue to provide and encourage flexibility with regard to DHHS funding being used to pay for the transportation costs of DHHS clients. This is an area where the joint guidelines would go far in ensuring DHHS programs retain their commitment to making adequate transportation resources available.

CONCLUSION

In closing, we again thank you for this opportunity to bring our message about the critical role public transportation can and does play in providing services to millions of Americans. We ask that in developing the fiscal year 2000 Labor, Health and Human Services and Education bill the Subcommittee:

—Direct DOT and DHHS to complete the joint coordination guidelines on human services transportation now being developed as soon as possible, following the example of the welfare-to-work guidelines;

—Highlight the role that public transportation can and does play in providing cost effective services for health and human service transportation activities, by providing and encouraging flexibility in DHHS funding being used to pay transportation costs; and

—Encourage health and human service providers to coordinate their transportation activities through the metropolitan transportation planning process.

PREPARED STATEMENT OF DAVID DAVILA, M.D., MEDICAL DIRECTOR, BAPTIST MEDICAL CENTER—SLEEP DISORDERS CENTER, REPRESENTING THE NATIONAL SLEEP FOUNDATION

The National Sleep Foundation (NSF) is a science-based, non-profit voluntary health organization dedicated to promoting awareness about the importance of good sleep, sleep disorders and the consequences of sleep deprivation. Our research tells us that nearly 60 million Americans at any given time are operating on inadequate sleep. Results from the "Sleep in America" poll, a nationally representative telephone survey conducted by the National Sleep Foundation and released earlier this month, show that 40 percent of Americans reported being so sleepy during the day that it interfered with their daily activities. The toll of sleep deprivation on human health, safety, and productivity is enormous. NSF and sleep experts like myself take this chronic sleep deprivation very seriously. NSF has been working with state and federal governments over the last six years to combat the dangers of drowsy driving and fall-asleep crashes through its DRIVE ALERT . . . ARRIVE ALIVE campaign.

Sleepiness—whether the result of untreated sleep disorders or simple sleep deprivation—has been identified as a causal factor in a growing number of on-the job injuries. Fatigue was cited by investigators as a contributing factor in disasters from the Challenger Space Shuttle explosion to the grounding of the Exxon Valdez. In fact, ten years after the Exxon Valdez disaster, we are still seeing the effects on Alaska's economy and environment. While many in the public and media tend to focus on reports that the Valdez's captain was intoxicated at the time, it was actually a sleep-deprived third mate who ran the ship aground in the Prince William Sound. In its official report, the National Transportation Safety Board stated, "The third mate's failure to turn the vessel at the proper time . . . probably was the result of his excessive workload and fatigued condition, which caused him to lose awareness of the location of Bligh Reef." Why we tend to overlook the obvious—that we are all human and need to get good sleep in order to maintain proper alertness on our jobs and in our life—is beyond me. The costs to the U.S. economy in lost productivity, personal injuries, medical expenses, property and environmental damage due to fatigue, sleep disorders and sleep deprivation exceeds $100 billion each year.

The National Sleep Foundation is a health organization. While good sleep is an important part of overall good health, our primary concern is the association between fatigue and the lapses in judgment and attention that result in injury. Sleep deprivation is dangerous, but preventable. Research conducted in recent years tells us that we can identify those people most at risk of sleep deprivation, and indicates how we can reduce injury due to fatigue. Unfortunately, fatigue or sleepiness is affecting all of us in profound ways in today's 24-hour society. In our "Sleep in America" poll, 62 percent of those surveyed stated that they had driven while drowsy in the past year. Even more importantly, 27 percent of adults stated that they had actually dozed off behind the wheel of a car in the past year. And an overwhelming 23 percent of adults in this survey stated that they personally knew someone who had been in a automobile crash due to falling asleep at the wheel in the past year. These crashes are often deadly and the injuries, if the person lives, are severe.

In Arkansas, we initiated a drowsy driving program called "Awake and Alert in the Natural State," which was well received by our State Police force and State Highway officials. By targeting people most at risk for drowsy driving and implementing effective countermeasures, we have begun to raise awareness in Arkansas, but we need help. NSF has led the way by building national campaigns like National Sleep Awareness Week that took place a few weeks ago and state campaigns like Wake Up! in New York State, the Shuteye campaign in California, and Heads Up at the Wheel in the Pacific Northwest. We would like to suggest to you today that these measures are worth examining more closely.

The NSF encourages you to support a provision of $1.2 million above the previous year's appropriation for the development of evaluative research, including data collection, through the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention. These funds would address sleep deprivation research and injury prevention associated with fatigue. I personally know that the Arkansas Department of Health would welcome such an expansion.

It is important to understand what NSF has done and how it is working. New York State in conjunction with NSF and other partners has taken the lead in conducting research on the scope and nature of drowsy driving and in developing effective countermeasures for driver fatigue. New York developed a standardized, medically accurate curriculum on the risk and prevention of drowsy driving and then used that material to provide training for traffic enforcement and safety professionals in the state. In Arkansas, NSF would like to model activities in New York, introducing other effective countermeasures such as comprehensive public awareness campaigns, aggressive programs to install shoulder rumble strips on interstate highways, and major initiatives to expand and upgrade public rest areas.

The National Sleep Foundation recognizes the importance of addressing fatigue as a public health issue in injury prevention. The general public does not understand the relationship between fatigue and injury, or the benefits of adequate sleep. Irrespective of educational level, 83 percent of adults failed a simple Sleep IQ test consisting of 11 questions. The National Sleep Foundation encourages the Subcommittee to support efforts to quantify the relationship between inadequate sleep and injuries through the CDC's National Center for Injury Prevention and Control.

Outreach through community injury prevention programs that involve traffic safety and public health organizations have also proven to be highly effective in reducing injury. We believe CDC's National Center for Injury Prevention and Control—with its emphasis on science as a basis for policy and its strong network of state injury prevention programs—should serve as the primary federal partner for these community programs.

Thank you for the opportunity to share our perspective with you. NSF would like to increase awareness and resources at CDC by requesting $1.2 million to address sleep deprivation research and injury prevention associated with fatigue. We appreciate the subcommittee's consideration of our request. If there are any additional questions on this issue, please contact Darrel Drobnich, NSF director of government affairs at (202) 347–3471.

PREPARED STATEMENT OF THE SAFETY NET COALITION

The Safety Net Coalition includes organizations which represent some of the largest providers of care to the uninsured across the nation. The Coalition urges your support for the $25 million safety net initiative included in the Administration's fiscal year 2000 budget request for the Department of Health and Human Services. This funding would support grants to local communities to enhance collaboration and cooperation among safety net clinics and hospitals, helping to produce a more efficient and seamless health care system for the uninsured.

Currently many very important federal programs provide direct support to providers of health care services for uninsured and underinsured populations. These programs play a vital role in their communities and need additional funding in their own right to serve the growing number of people who are seeking their care. While such funding will strengthen the foundation of care for uninsured and vulnerable people in many communities, safety net providers could be even more efficient and cost-effective if given the resources to work together and coordinate care for their patients. Currently, there is no federal support for communities wishing to integrate the programs and services they already provide into a cohesive system of care for uninsured patients. While safety net providers are committed to providing the best possible coordinated services, they face significant obstacles in doing so. Their patients typically have much greater and costlier medical and social needs than more affluent populations, sapping these providers of any disposable resources to devote

to coordinating care among themselves. The safety net initiative would help fill service gaps, building upon existing programs by encouraging coordination and efficiency and thereby significantly stretching federal dollars invested in direct services.

Moreover, the initiative would allow for significant innovation and experimentation at the local level, with local consortia of providers proposing the most effective use of the funding for their communities. By focusing on the most pressing service gaps in their communities and targeting true safety net providers—those who currently serve large numbers of low-income and uninsured patients—communities can guarantee that existing charity care is expanded, and not supplanted or replaced. Successful models already in existence could be replicated or adapted, or communities could design completely new approaches. In addition, communities could use the relatively modest federal investment to leverage even greater local public and private funding, eventually becoming self-sustaining.

We believe that this initiative is a sound and prudent investment of admittedly limited federal funding that will reap benefits far exceeding its costs in terms of enhanced care and improved efficiency. The following members of the Safety Net Coalition urge you to support this funding: American Association of Medical Colleges; American Association of Physicians of Indian Origin; American College of Nurse-Midwives; American Physical Therapy Association; Asian & Pacific Islander American Health Forum; Association of Maternal and Child Health Programs; Association of University Programs in Health Administration; California Association of Public Hospitals and Health Systems; Catholic Health Association of the United States; Latino Council on Alcohol and Tobacco; National Association of Children's Hospitals; National Association of Community Health Centers; National Association of Counties; National Association of Public Hospitals & Health Systems; National Coalition for the Homeless; National Family Planning & Reproductive Health Association; National Health Care for the Homeless Council; Service Employees International Union; The Alan Guttmacher Institute; The Association of Reproductive Health Professionals; and The National Native American AIDS Prevention Center.

PREPARED STATEMENT OF PHILLIP E. STEPHENS, NATIONAL BLADDER FOUNDATION

Honorable Chairman and Members of the Committee: Thank you for giving the National Bladder Foundation the opportunity to submit written testimony about the devastating effects of bladder diseases in this country. We request your help in funding research to cure them. Below please find the personal testimony of interstitial cystitis patient Phillip Stephens which was presented in person before the House Appropriations Sub-Committee of Labor, Health and Human Services on April 15, 1999.

My name is Phillip Stephens. I have interstitial cystitis. For most of my working life I have been in real estate, developing shopping centers and other commercial properties around the Southeastern United States. I live and work in Atlanta, Georgia and am the Chairman and CEO of Stephens Property Group. In 1990 I was on my honeymoon in the South of France when I began to experience a burning, pinching sensation in the area of my groin. I was 43 years old and it was my first marriage. I had no idea what could be wrong with me and must tell you, I wondered if my former girlfriends were trying to get even or something.

Like so many men with IC, my problem was incorrectly diagnosed as benign prostate enlargement or BPH and for two years I took the usual battery of medicines prescribed for this malady—nothing helped and I was in pain 24 hours a day. Finally, in 1992, I had the first of two surgical procedures to relieve prostate enlargement. These did nothing to help. I was then bounced around to several other urologists who all prescribed the same ineffectual medicines. Still nothing helped and I lived in excruciating pain, needing to urinate constantly.

Because the classic symptoms of many bladder diseases are frequency of urination and the feeling of urgency i.e. the need to urinate, many, many, patients get misdiagnosed and like me are forced to go from doctor to doctor and even from medical specialty to medical specialty. In the past, women were routinely told that "it was all in their heads" and told to try to relieve the stress in their lives. In my case, once they had more or less ruled out that I did not have BPH—the most common reason men my age would experience my bladder symptoms—I was referred to a psychiatrist for "stress management". It turned out that the psychiatrist was Atlanta's leading authority on criminal deviate sexual behavior. You can only imagine the cast of characters I shared the waiting room with. But the doctor was perfectly prepared to take my money and recommended a treatment program of sexual therapy. Although I kept insisting that I needed relief for my horrible pain, my cries went unheard and only psychological assistance was offered. By then I was desperate and

I found out that when a person is truly desperate, he will put up with almost anything.

Finally, in June 1996—almost four years after I first began to experience the pain symptoms, I went back to my original urologist and underwent yet another surgery for benign prostate enlargement. When I woke up in the recovery room, the doctor told me I had interstitial cystitis and that there was no cure for the disease. Although this news was not happy, at least I finally had a name for my disease.

Interstitial cystitis is an inflammation of the bladder wall and may affect up to 1 million people in the United States—most of its patients are women—approximately 10 percent are men. In my case, like in Terry-Jo Myers' the LPGA golfer with IC, the new oral medication Elmiron, has improved my symptoms and has allowed me to be here today to represent those too ill to leave their homes. Unfortunately the drug is not effective for the majority of patients, many of whom live in constant pain, often housebound. I am also lucky, unlike many patients, to be able to afford to have access to the many doctors I had to seek out before I got a correct diagnosis. You may know that while interstitial cystitis cannot kill you, a tragic number of its victims resort to suicide—the pain and sense of helplessness they feel leads to a diminution in their quality of life which becomes just too much for some people to bear.

Bladder disease affects a part of the body which most of us are embarrassed to talk about. I can't tell you how hard this was for me to deal with. I had a wonderful time as a bachelor for twenty years and to finally marry the woman of my dreams only to be afflicted with this disease starting on my honeymoon reduced whatever male ego I did have by quite a wide margin. As a man with IC, Senator Dole's ads on National TV for Viagra have been an inspiration to me and I know it has been for many others as well.

It is estimated that over 35 million people suffer with bladder disease in the United States—over 1 in 10. Bladder cancer is the 4th leading cause of new cancer in men with—40,000 new cases this year. The link between smoking and bladder cancer has been established and this needs to be much more widely publicized. The number of doctors visits for urinary tract infections, almost 10 million, is second only to respiratory infections. Over 1.5 million people are hospitalized for UTI's each year and for spinal chord injury patients such infections may be fatal. But the largest segment of the bladder disease population has incontinence. Half of all women experience incontinence at some point in their lives and ⅓ develop a regular problem. It is a major factor in nursing home admissions. Like IC, there are huge social and psychological consequences with incontinence. 50–70 percent of women with urinary incontinence will fail to seek medical help because of embarrassment and shame. They rely on absorbent products when a variety of treatments are available. Incontinence affects about 25 million adults and the cost of its care is estimated at $16 billion annually. Finally, childhood bladder disease affects a huge number of children. 5–7 million kids suffer from enuresis or bedwetting and pediatric reflux affects 10 percent of all babies. Reflux is characterized by the reversal of urine flow and this can result in severe infection and kidney destruction. Studies indicate that the incidence and prevalence of bladder disease promises to increase dramatically in the next fifteen years.

We need your help in finding causes and cures for bladder disease—diseases that affect over 13 percent of Americans young and old. Statistics suggest that bladder disease research is profoundly under-represented in NIH research funding. Only 41 cents is spend at the NIH on bladder disease per afflicted patient compared to other diseases such as lupus where $35 is spent, heart disease where $74 is spent and Alzheimer's where $81 is spent per afflicted patient.

The National Bladder Foundation and all bladder disease patients are so grateful to all Members of this Subcommittee and in particular, to Chairman Spector, for his ongoing and support of IC research and other urological diseases. We respectfully urge you increase the funding for all bladder diseases including interstitial cystitis at the NIH and ask:

1. That additional funds be provided to the Urology Program of the NIDDK in fiscal year 2000 to substantially enhance its research effort on bladder disease through all available mechanisms.

2. That the NIDDK issue a series of RFA's specifically for basic bladder research, intersitial cystitis and incontinence in fiscal year 2000 and designate funds for that purpose;

3. That the NIDDK establish bladder research centers to develop therapies for the 35 million Americans suffering with bladder disease.

Please help us end the suffering of IC and all bladder disease. Thank you so much for supporting research into bladder disease.

PREPARED STATEMENT OF W. RON ALLEN, PRESIDENT, NATIONAL CONGRESS OF AMERICAN INDIANS

I. INTRODUCTION

Chairman Specter, Vice-Chairman Harkin and distinguished members of the Appropriations Subcommittee on Labor, HHS, Education and Related Agencies. Thank you for the opportunity to present this statement regarding the President's Budget Request for fiscal year (FY) 2000 Indian programs and services specifically in the Departments of Labor, HHS, and Education. My name is W. Ron Allen. I am President of the National Congress of American Indians (NCAI) and Chairman of the Jamestown S'Klallam Tribe located in Washington State.

NCAI views the fiscal year 2000 federal budget process as an opportunity to begin to set a better course for federal Indian policymaking in the next century. Tribal governments have found themselves in an increasingly defensive posture in the development of federal Indian policy over the last four years, and budget cuts and budget riders have been the point of attack on tribal self-determination.

Tribal leaders have set as an important goal that the tribal budget must become a higher priority within the appropriations process. The federal government has treaty and trust obligations to support Indian tribes that it is simply not meeting. Also, tribal citizens pay federal taxes but receive little support from federal funds that go to states. Programs serving the American Indian and Alaska Native population have rarely received the federal funding required to fulfill even the most basic needs and funding for Indian programs has lagged far behind the funding of non-Indian programs. Compared to all other sectors of the American populace, American Indians and Alaska Natives most often rank at or near the bottom or top of most social and economic indicators, whichever is worse. Of the 558 federally-recognized Indian tribes, a great majority of their populations are characterized by the most severe unemployment, poverty rates, ill-health, poor nutrition and sub-standard housing in the U.S. In an era of federal budget surpluses, there are no excuses for failing to meet the federal obligation to remedy the human tragedy behind the statistics.

The solution for the poor conditions in Indian Country must be a reinvigorated approach to economic development. The federal budget for fiscal year 2000 can do much to build the necessary infrastructure of roads, schools, housing, child and elder care, hospitals, clinics, technology, law enforcement, courts and other critical elements of any functioning economy in the United States. The United States has an obligation to help rebuild the shattered infrastructures of Indian Nations and create the opportunity for economic prosperity that will benefit not only Indian people, but the entire American economy. It should also be noted that the conversion of welfare entitlement funds into state discretionary funding has added to the urgency felt throughout Indian Country to boost economic development.

Also, the use of appropriations riders to ambush tribal self-government has become more and more frequent. Tribal self-government is recognized in the United States Constitution and hundreds of treaties, federal statutes and Supreme Court cases and is deserving of serious consideration by the Congress. At the very least, if the federal government is going to contemplate legislation affecting tribal self-government, the legislation should be considered in the authorizing Committees, given opportunity for consultation with the affected tribes, and taken up as stand-alone legislation where Members of Congress can know and understand what they are voting on. We have been made aware of the introduction of Senate Resolution 8 by Senators Ted Stevens and Robert Byrd. S. Res. 8 would amend the Senate rules to reinstate a former rule which prohibited legislative riders on appropriations bills and which would require a three-fifths vote to waive a point of order under the rule. NCAI would surge the members of this Sub-committee to support S. Res. 8.

As Congress begins to shape the fiscal year 2000 budget, the NCAI urges an increased investment in Indian programs and tribal government infrastructure. We believe that the President's fiscal year 2000 budget request has taken a very positive step in that direction. The following testimony is an overview of the recently released President's fiscal year 2000 budget request that provides NCAI's viewpoint on sections of the budget that are most critical to tribal governments.

II. BACKGROUND INFORMATION

Mr. Chairman, I would like to begin my testimony by providing a general context regarding federal funding for Indian programs. Unfortunately it has been a rare occasion indeed, if ever, that programs serving the American Indian and Alaska Native population have received the federal funding required to fulfill even the most basic needs of tribal members. Of the 558 federally-recognized Indian tribes, a great

majority of our populations are characterized by severe unemployment, high poverty rates, ill-health, poor nutrition and sub-standard housing. Historically, funding for Indian programs has lagged far behind the funding of many non-Indian programs and this gap only continues to grow.

Compared to all other sectors of the American populace, American Indians and Alaska Natives most often rank at or near the bottom or top of most social and economic indicators, whichever is worse. When comparing trends between fiscal year 1975–1999 for the total BIA budget and the federal non-defense budget as a whole, federal spending as a whole increased at a rate of $41 billion a year, with an average level of $669.8 billion, while when corrected for inflation, the BIA budget actually declined by $10 million a year, on an average spending level of $1.7 billion. Throughout the entire fiscal year 1975-fiscal year 1999 period, per capita spending on the U.S. population as a whole consistently increased, whereas per capita spending on Indians through major Indian-related programs began to fall after fiscal year 1979.

Furthermore, in fiscal year 1996, federal funding for Indian programs fell short 13 percent or $581 million from the President's budget request for that fiscal year. This was mostly seen in dramatic cuts in funding for the BIA ($322 million less), Department of Housing and Urban Development (HUD) New Indian Housing ($134 million less), and the Indian Health Service (IHS) ($80 million less). In fiscal year 1997, funding for these programs fell short 4.1 percent or $175 million below the President's request. And in fiscal year 1998, there was a 1.2 percent or $52 million shortfall from what the President requested. In fiscal year 1999, this unfortunate trend continued with a $100 million shortfall.[1] Mr. Chairman, in a year when the U.S. economy is booming and the federal government is expecting over seventy billion dollars in surplus funds, the federal government should not be cutting funds to American Indians, this nation's poorest people.

As you are well aware, in recent years tribes have faced extraordinary challenges throughout the appropriations process. Unprecedented reductions in federal Indian program funding left many tribes facing extreme circumstances. Non-funding "riders" attached to Interior Appropriations bills reached well past the scope of the appropriations process and were interpreted by Indian Country as an attempt to diminish tribal sovereignty and change the basic fabric of the federal-tribal relationship. While we appreciate the commitment to balance the federal budget and reform the welfare system, we maintain that such laudable initiatives do not and should not preclude the federal government from fulfilling its trust responsibilities to Indian tribes throughout this great nation. In short Mr. Chairman, extraordinary budget reductions in federal Indian programs have created a state of emergency for many tribal governments. NCAI is encouraged, however, with the Administration's fiscal year 2000 commitment to begin addressing some areas of priority concern to Indian Country.

As Congress begins the appropriations process for fiscal year 2000, NCAI aggressively seeks support from this Subcommittee in reversing the decline in funding for federal Indian programs that we have experienced since fiscal year 1996. In general, we believe that the President's fiscal year 2000 budget request has taken a very positive step in this direction. We are concerned, however, that even the Administration's request for certain essential tribal programs and services remain seriously inadequate. Accordingly, tribal budgets are insufficient to meet the most basic needs of tribal populations.

The following testimony is an overview of the recently released President's fiscal year 2000 budget request that provides NCAI's viewpoint on sections of the budget under the Department of Agriculture that are most critical to tribal governments. As more specific information is released from the Administration regarding the details of the budget request, NCAI will provide further information regarding the priorities of the tribal government members of NCAI.

A. Department of Labor

With the enactment of the Workforce Investment Act (WIA), the enduring Job Training Partnership Act (JTPA) has been repealed; most of its various job training programs were redesigned and incorporated into the new WIA programs. WIA includes tribally specific programs with guaranteed funding levels for such programs. However, the President's fiscal year 2000 budget request for tribal WIA programs is $1.2 million less than the Indian program is guaranteed in the authorization statute. NCAI urges Congress to fully restore the guaranteed authorized funding level

[1] See generally "Indian-Related Federal Spending Trends, Fiscal Year 1975–1999", Congressional Research Service (CRS), February 1998.

for Indian WIA programs which urgently needs funding for job training and related support services.

NCAI also requests the Congress to reauthorize the Welfare-to-Work (W-t-W) program for tribes an additional two years and to increase the funding level for this program by an additional $30 million. Well over 65 WtW plans for tribal programs have been submitted to the Division of Indian and Native American Programs, with slightly over 100 tribes, intertribal consortia and Alaska Native villages covered under these plans. Extension of this program is critical, along with a much-needed funding increase, in order to provide employment services for long-term welfare recipients into the next millennium.

The Senior Community Service Employment Program (SCSEP), authorized in Title V of the Older Americans Act (Pub. L. 89–73, as amended), provides important services for Indian elders. The SCSEP funds ten national sponsors, including the National Indian Council on Aging (NICOA), to train low income elders through community service agencies. NCAI requests an appropriation of $484 million, a 10 percent increase, for Title V programs in fiscal year 2000, and maintenance of the provision for a guaranteed minimum allocated to the program serving Indian elders. The Title V program is especially important for Indian Country due to the significant need for many Indian elders to acquire job skills and supplement their very limited incomes, the high rates of unemployment found in Indian Country, and the great need for the community services these trainees provide.

B. Department of Health and Human Services

1. Indian Health Service

a. Fiscal year 2000 funding

After last year's unacceptable $2.1 billion budget request, an 1.9 percent increase, for the Indian Health Service (IHS), a request that was eventually increased to $2.7 billion by Congress to better support tribal health care needs, the President's fiscal year 2000 budget request of $2.8 billion is a step in the right direction. However, this total includes an estimated $39 million in Medicare, Medicaid and Private Health Insurance collections, making the adjusted Administration's request somewhere in the area of only $2.412 billion. This adjusted total falls short of the requested minimum of $2.62 billion tribal governments advised the Administration and Congress to enact, minus any estimated health insurance collections, per NCAI Resolution #MRB–98–097 (attached).

A brief analysis of the President's budget request quickly identifies additional funding needs. The IHS reports that currently enacted funding levels only serve 36 percent of the projected need for Indian health care. Moreover, IHS statistics show a current inflationary rate that will require an additional $30 million to compensate for current inflation alone. The $400 million in increases to the fiscal year 2000 IHS budget listed below will help to significantly address outstanding funding needs in areas such as Contract Support, medical inflation rates, and program funding shortfalls. NCAI urges Congress to increase the President's fiscal year 2000 IHS budget in the following categories:

[In millions of dollars]

Hospitals and Clinics	76
Contract Health Services	33
Contract Health Representatives	5
Contract Support Costs	100
Other Health Service Programs (including Urban, Dental, Mental Health, Alcohol/Substance Abuse Prevention, etc.)	100
Facilities (including Construction, Sanitation andMaintenance & Improvement)	100

What these requested funding increases mean, in real terms, is that thousands of American Indian and Alaska Native people will have access to better and more increased health care services including hospital admissions, outpatient visits, dental services, mental health and social health services, public health nursing home visits and community health representative visits.

b. Contract Support Costs

The President's budget request includes a $35 million increase in contract support associated with IHS programs under tribal operation. Based on current levels of contracting, such an increase would certainly boost the levels of contract support payments to many tribes. But even if inflation is disregarded, it would still leave scores of the least funded tribes underfunded in the range of between 10 percent and 20 percent, depending upon which of several possible methodologies is used to

distribute such an increase. (Possible methodologies include helping all underfunded tribes cover varying shares of their shortfall, as well as methodologies directing all such new funds only to the most severely underfunded tribes.)

At this time, it is unknown whether Congress will lift the section 328 moratorium, in whole or in part. For its part, IHS is now actively exploring with Indian Country possible alternatives, including approaches which view fiscal year 2000 as a second "transition" or "correction" year in which the vast majority of any effort continues to go toward addressing the ongoing contract support crisis faced by existing tribal programs. These and other reform issues are being actively explored as part of IHS's initiative to revise the agency's contract support cost circular for fiscal year 2000 by April 1999.

As with the BIA shortfall, the NCAI Workgroup on Contract Support Costs has strongly urged Congress to fully close the gap in the current IHS shortfall for fiscal year 2000, estimated by IHS to be $93.4 million plus unfunded pre–1999 inflation. As part of this effort Congress should restore the Indian Self-Determination Fund to at least $12.5 million in fiscal year 2000, and IHS should immediately begin canvassing Indian Country to secure an assessment of new contracting requirements needed for fiscal year 2000 and fiscal year 2001.

c. Contract Health Services

Contract health is an important component of Indian health programs, particularly in areas without IHS hospitals, where there is rapid business development, and where there are smaller tribes that tend to be contract health services dependent due to a lack of clinical services. To highlight the impacts of continued contract health funding shortages, the Great Lakes Intertribal Council did a Wisconsin tribes' study that identified sizable cost shifts to tribes, averaging around $400,000 per tribe, per year for contract health services. These shifts equate to an approximate 70 percent shortage of federal funding for tribal contract health programs. The Wisconsin study also identified $2.6 million in tribal contributions per year to cover these cost shifts, an amount equal to the funding levels Wisconsin tribes received from the IHS. This snapshot of contract health funding shortages in Wisconsin is a good example of the contract health funding shortages experienced by tribes in most other areas of Indian Country.

Vice Chairman Inouye eluded to the concerns over cost shifting contract health costs to tribes in his statement on Indian health care issues before this committee on May 21, 1998. Moreover, NCAI Resolution #GRB–98–039 (attached) requests that Congress end the impacts of cost shifts to tribes by increasing funding for contract health by 70 percent, the amount identified by the fiscal year 2000 Indian Health Service Budget Tribal/IHS Task Force, and encourages further study of the issue of cost shifting, particularly for contract health services, by Congress and the IHS.

d. Urban Indian Health

With nearly half of the nation's Indian population living off-reservation in the urban areas of this country, the funding needs of urban health clinics continue to grow. The President's $3 million increase in Urban Health services is a welcomed improvement. Tribal governments continue to share in the duties and responsibilities of providing health care for urban Indian individuals in conjunction with the federal government. For these reasons it is critical that our clinical services, whether they be provided by the IHS, the tribe, or the urban Indian clinic, continue to receive increased funding to keep pace with the ever-increasing needs of their service area populations.

e. Indian Health Care Improvement Fund/Comprehensive Health Emergency Fund

Under the President's $12 million budget proposal for the Indian Health Care Improvement Fund, $4.9 million will be lost in Special Pay Funding (physician compensation). NCAI requests an additional $13 million be allocated to this important program, allowing IHS hospitals to compete with the private sector in attracting top quality physicians. In addition, NCAI Resolution #MRB–98–116 (attached), calls upon Congress to increase the regular IHS scholarship appropriation from $9.6 million to $20.9 million, providing the necessary funding to accommodate an additional 432 health professional students in fiscal year 2000. NCAI also requests an additional $8 million be added to the President's $12 million request for the Comprehensive Health Emergency Fund, bringing that fund's total up to the level requested by tribes to meet the projected need in Indian Country.

f. IHS Medicaid Per Capita Expenditures

As reported to Congress last year, a growing disparity exists between Indian and non-Indian citizens in per capita expenditures for Medicaid patients. Current IHS

Medicaid statistics reflect a $3,300 per capita expense for non-Indians, compared with a $1,400 per capita expenditure for Indian patients, a difference of nearly $2000 less expended on Indian Medicaid patients. Per NCAI Resolution #MRB–98–111(attached), Congress is urged to allocate funding levels necessary to close the enormous disparity in the per capita amount of health care costs associated with IHS hospital facilities throughout the nation, a move that will help balance out the inequities between Indian and non-Indian per capita Medicaid expenditures.

g. IHS Facilities Funding

Tribes have reported to NCAI that recent fiscal year decreases in overall federal funding for IHS Facilities maintenance and construction have left facilities struggling to keep pace with the needs of their service areas. Old facilities continue to experience the need for major improvements, and some service areas have grown to the point of requiring the construction of new facilities. NCAI has two resolutions that address IHS Facilities funding needs. The first, NCAI Resolution #MRB–98–099 (attached), calls upon Congress to funding for the construction, maintenance and improvements of health care facilities. The second, NCAI Resolution #MRB–98–015 (attached), seeks an additional $1.5 million in operating funds for the Lawton Hospital in Oklahoma. This funding is necessary to better staff and operate the only accessible hospital for several tribes in western Oklahoma.

Most IHS facilities throughout Indian Country require specific, quantified levels of funding to operate effectively and efficiently for the patients they serve. Many of these facilities, like Lawton, are the only upper-level health care facility in close proximity to remote tribal communities. Congress must continue to address the growth of tribal health service populations and the health care facility funding needs associated with that growth. To abandon this commitment will create turmoil and confusion within the regions that tribal, IHS and urban health care facilities serve. NCAI urges Congress to support the need for increased health care facilities in Indian Country by increasing the President's fiscal year 2000 budget request for IHS Facilities funding by $100 million.

Sanitation facility needs continue to grow in the more remote parts of Indian Country, and especially in Alaska Native villages. With over $1.687 billion in sanitation deficiencies identified by the IHS as of fiscal year 1998, the President's requested increase of $3 million falls short of any realistic commitment to improve tribal sanitation services. NCAI urges Congress to appropriate an additional $10 million in IHS sanitation facilities funding, with $5 million earmarked for the Alaska honey-pot eradication project.

h. Y2K Initiative

The integrity of IHS/Tribal/Urban Indian (ITU) health care information systems are compromised by the Year 2000 (Y2K) computer problem. Congress approved funding for fiscal year 1999 to begin addressing the magnitude of problems surrounding Y2K. NCAI Resolution #MRB–98–038 (attached) urges Congress to continue Y2K funding in fiscal year 2000, allocate a portion of those funds to the Indian Health Service to adequately address the number and diversity of ITU health information systems, and direct the IHS area offices to conduct full consultation with ITU's over the distribution of such funding.

i. IHS 638 Moratorium

In fiscal year 1998, a one-year moratorium on Pub. L. 93–638 contracting and compacting of IHS programs was enacted as part of the fiscal year 1998 IHS appropriations (Section 326). This moratorium was extended through fiscal year 1999 as part of last year's IHS appropriations law (Section 341). NCAI went on record both years opposing such moratoriums. NCAI Resolution #MRB–98–046 (attached) also opposes Section 341 of the fiscal year 1999 IHS Appropriations law as a direct assault on tribal sovereignty by eliminating the rights of Alaska tribal governments to contract or compact. This resolution also considers the moratorium an impediment to Congress' intent of expanding self-determination in Indian Country, and contrary to the government-to-government relationship between tribes and the federal government. NCAI urges Congress to repeal the IHS "638" moratorium and oppose any legislative initiatives that would weaken any tribal authority to contract or compact.

j. Tobacco Settlement

Tobacco Settlement legislation was a major legislative initiative in the 105th Congress, and one that tribal governments took notice of early on. IHS statistics show that Indian people suffer from tobacco related illnesses in far greater numbers, per capita, than any other population sector in the United States. Because of this, NCAI's member tribes adopted NCAI Resolution #GRB–98–011 (attached) that sup-

ports provisions which would allocate a fair share of any new taxes or funds resulting from a tobacco settlement to the IHS budget. This resolution also calls upon the IHS develop a tribal consultation process for the distribution of any funds resulting from increase tobacco taxes or tobacco settlement monies, and, should funding be directed to state governments only, that states be required to fund tribes at an equitable level for tobacco related illnesses.

k. IHS Self-Governance Program

NCAI lauds the work of the U.S. House of Representatives in last year's passage of H.R. 1833, which would establish permanent authorization of the IHS self-governance program. Such legislation was developed by tribal self-governance and non-self-governance leaders, the IHS and the DHHS policy staff. NCAI Resolution #GRB–98–014 (attached) formally calls upon the Congress to consider and approve the passage of permanent authorization for the IHS self-governance program as quickly as possible.

l. Elevation of the IHS Director

NCAI Resolution #GRB–98–010 (attached) also urges Congress to elevate the IHS Director position to that of Assistant Secretary within the DHHS. Currently, the Director of the IHS, the top administrative official charged with carrying out the federal responsibility for Indian health, does not report directly to the DHHS Secretary. NCAI, along with tribal leaders and tribal health care professionals feel that in order for the IHS to operate efficiently and effectively and have its needs best served by the DHHS, that the head of the IHS must be elevated to the level of Assistant Secretary. NCAI urges Congress to pass such legislation early on in the 106th Congress.

m. Tribal Participation in IHS fiscal year Budget Development

Along with the $2.62 billion IHS fiscal year 2000 funding level request mentioned above, NCAI Resolution #MRB–98–097 (attached) charges the NCAI to urge Congress to direct the IHS to work collectively with NCAI, tribal governments, the National Indian Health Board, the IHS Tribal Self-Governance Advisory Board, the National Council on Urban Indian Health and regional Indian health boards to develop an IHS budget that adequately addresses the significant needs in health care throughout Indian Country. Quality health care continues to be one of Indian Country's top priorities. It is common knowledge that the IHS has been historically and grossly under-funded, leading to inadequate medical services, facilities and treatment programs within many reservations and urban Indian communities. Because of this, Indian people continue to suffer the highest levels of chronic diseases, infant mortality, teen suicide and substance abuse than any other population sector in the nation.

Over 1.5 million American Indians and Alaska Natives receive health care services from the IHS. In many remote areas of Indian Country, IHS services are the only health care services available. As unacceptable as Indian health care statistics were during times of enormous federal deficit, such statistics are absolutely unconscionable in times when the federal government enjoys a sizable budgetary surplus. Congress is urged substantially increase the IHS budget as a way of improving the status of Indian health and meeting the rise in projected health care needs throughout Indian Country.

2. Administration for Native Americans

a. ANA Program Overview

ANA administers its basic grant program in four distinct categories, including: (1) the Social and Economic Development Strategies program (SEDS); (2) an Alaska specific SEDS program primarily geared to governance; (3) an environmental regulatory enhancement program focused on tribal capacity building; and, (4) the native language program to preserve and revitalize native languages. The SEDS program includes a wide range of governance projects allowing for tribal constitution revisions and codes/ordinance development, social projects that are based on maintaining and fostering cultural traditions, and economic development projects covering a wide range of areas.

ANA economic development projects include not only the development of new enterprises but also the expansion of existing successful businesses. The majority of economic development projects are planning grants for architectural and engineering costs or grants that provide for economic development infrastructure (i.e. codes/ordinances development and creation of enterprise boards).

b. New ANA Initiatives

In fiscal year 1999, ANA began requiring a 401-(k) retirement plan for approved applicants funded by ANA. As a part of the fringe benefits package provided by the tribe to employees under the ANA project, ANA will fund at least five percent of the employer's share. This initiative will assist in creating a positive and viable retirement system in Indian Country and has received support from a sampling of tribes.

ANA has also leveraged an additional $1 million in ANA funding along with $1 million from the state of Hawaii for a total of $2 million awarded in grants under the Native Hawaiian SEDS specific program. This program will assist Native Hawaiian communities in meeting their unique social and economic development goals.

c. Impediments to ANA Program Grant Expansion

ANA has been at level funding at 35 million dollars since 1995. In real terms this means that ANA has lost 20 percent of program dollars due to the inability of the budget to keep pace with inflation. Under current budgetary conditions, the ANA can fund only about 25 percent of the grant applications submitted for each program. ANA could, however, fund many more grants if funding were available. In fiscal year 1998, for example, ANA received 549 applications but was only able to award 188 new starts.

Since 1994, ANA has also lost 50 percent of its staffing. Of this total, one third has taken place in the current fiscal year. ANA has gone from 33.5 FTE to 16 FTE since 1994. In keeping with Native American preference in hiring, ANA planned on hiring Native Americans in those vacancies that were lost. However, budgetary reductions have stymied that goal. Staff cuts have also negatively impacted the ANA workload both in terms of customer service and necessary monitoring and analytical work on grant awards. FTE reductions have also impacted the mission of the Intra-Departmental Council on Native American Affairs, chaired by the ANA Commissioner.

Through its Native American program assistance, the ANA has moved many tribal and Native programs from dependency on federal services, or operating federally-mandated programs, to developing and implementing their own discrete projects. ANA continues to serve a large and diverse base of Native American communities and organizations, many of which have little in the way of resources and lack sustainable economic development opportunities. NCAI urges Congress to increase the President's fiscal year 2000 budget request of $35 million for this agency to allow for increased grant awards and additional ANA staff. In doing so, Congress will show its support for the tribal self-sufficiency goals promoted by the ANA.

3. Administration for Children and Families

Within the Administration for Children and Families lies a host of Agencies, Bureaus and Divisions that regulate social service programs which are critically needed in Indian Country. Unfortunately, access to these programs and services is extremely limited, with tribal resources and consultation measuring only a fraction of what is provided to states and other non-tribal government entities. Agencies established for the purpose of serving tribal governments suffer the same dilemmas as tribes—i.e., the Division of Tribal Services (DTS), established under the DHHS/ACF to fulfill the requirements of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA, Pub. L. 104–193).

The President's fiscal year 2000 budget request again fails to provide the Division of Tribal Services (DTS) its own discretionary program authorization and budgetary line-item. Because of this, the DTS continues to be forced to borrow scarce resources from other agency programs in order to provide services to tribal governments in the areas of Temporary Services for Needy Families (TANF) and Native Employment Works (NEW) programs. The ACF has tried to provide necessary funding to carry-out these duties, but it has become more and more obvious that without line-item funding authorization for the DTS, the ever-increasing needs of Indian tribes surrounding these social support programs will not be met.

NCAI again urges Congress to immediately authorize for fiscal year 2000, an initial $10 million budgetary line-item for the DTS. As part of this authorization, NCAI again asks Congress to expand the DTS responsibilities beyond just TANF and NEW, to include social support related tribal services under the ACF including child care, child support and enforcement, and child protection services. Creating a more streamlined approach to serving tribal government social support program needs will benefit all parties involved in providing, obtaining and accounting for these services. NCAI also calls upon Congress to hold oversight hearing on welfare reform's impacts on Indian country. In this way, tribal leaders can report directly

to Congress on their needs, goals and objectives surrounding the conversion of tribal cash assistance populations into tribal workforce populations.

Tribal governments have passed a series of NCAI resolutions pertaining to the lack of direct programs, services, and funding authority within the ACF. Most are tribal TANF specific, but others cover children's issues, disabilities, etc. The following is a brief description of these resolutions.

When welfare reform was enacted, provisions in the law called for state and tribal TANF grant funding levels to be based on fiscal year 1994 AFDC enrollment figures of those state and tribal populations. It was quickly apparent that accurate data from state AFDC programs did not identify Indian AFDC recipients from non-Indian recipients. Additionally, many tribes who chose to operate tribal TANF programs soon realized that their TANF caseloads were far exceeding the estimated fiscal year 1994 caseload numbers. To formally address this issue, NCAI Resolution GRB–98–021, calls upon Congress to amend the PRWORA to allow tribes the option of basing their TANF grant funding level formula either upon: (1) fiscal year 1994 AFDC enrollment levels, (2) the level of actual enrollments based on a tribe's experience in the first year of operating its TANF program, or (3) the current level of actual enrollment. In this way, tribes will be assured that they will receive appropriate funding levels to effectively administer their TANF programs.

Many tribal communities are located in remote areas, with little in the way of public transportation services, creating very limited access to welfare-related support services and programs not directly administered by a TANF agent. Such programs may include Medicaid services, the Food Stamp program and others. To help consolidate these program and service deliveries, NCAI Resolution GRB–98–046 calls upon Congress to create a one-stop shop option for tribal TANF offices wishing to provide other support services not directly related to TANF for their eligible members and service area populations. This one-stop shop concept would allow Indian people to receive such services as Food Stamps from their TANF office, along with having their eligibility determined for programs such as Medicaid.

Consultation with tribal governments over federal Indian program regulations have always been minimal outside of the traditional BIA/IHS regulatory arena. Such lack of consultation has been the experience of tribes with the promulgation of tribal TANF regulations. This runs counter to the President's Executive Order No. 13084, which calls for increased direct consultation between tribal governments and the federal government over issues such as regulatory development. Because of this lack of consultation with tribes over the tribal TANF Notice of Proposed Rule Making (NPRM), NCAI Resolution MRB–98–057 calls upon the Administration to suspend the promulgation process until tribes have been consulted with in a manner mutually agreed upon by tribes and the NCAI. NCAI Resolution MRB–98–059, also highlights specific changes to the current tribal TANF NPRM requested by tribes. We ask Congress to support these tribal positions by directing the Administration to seek further consultation with tribes over any further tribal TANF regulatory process as well as any other federal regulatory processes that directly impacts tribal programs and services.

In regard to the development of tribal Child Support and Enforcement programs, the PRWORA authorizes tribal government to apply for direct funding over an entire tribally-operated Office of Child Support and Enforcement (OCSE) program, or direct funding for OCSE program functions carried out by the tribe as part of a cooperative agreement with the state over child support enforcement activities. However, the OCSE has stated to tribes that they would not authorize any direct tribal OCSE funding until after regulations over such tribal program functions are promulgated. NCAI Resolution MRB–98–067 requests the OCSE provide funding prior to a final rule being promulgated so that tribes can immediately begin building the infrastructure and technological base to operate such a complex program. NCAI urges Congress to direct the OCSE to adhere to the request of tribal governments under this resolution.

Our disabled Native American population continues to suffer from a lack of attention by the Congress and the Administration. Disability cases in Indian country far exceed those in other population sectors on a per capita basis, with many being disabled veterans. NCAI wishes to highlight three resolutions that speak to the needs of our disabled people.

First, NCAI Resolution GRB–98–042, calls upon Congress to work with the Administration, and specifically, the National Institute on Disability Rehabilitative Research (NIDRR), the U.S. Department of Justice (DOJ), the Rehabilitation Services Administration (RSA) and the Administration on Children and Families (ACF) to establish and fund an American Indian Americans with Disabilities Act (ADA) Technical Assistance Center to serve American Indians and Alaska Natives, respectful of tribal sovereignty and cultural diversity.

Second, NCAI Resolution GRB–980–043, urges the NIDRR to meet tribal needs for assistance with persons with disabilities by funding no less than three Research and Training Centers (RTC's) to work with tribal people and their governments, both on and off the reservation, in health, rehabilitation, and employment issues. NCAI urges Congress to direct the NIDRR to comply with the requests identified in this resolution.

Finally, NCAI Resolution GRB–98–050, calls for the support of a National Wheelchair Recycling Project, similar to a model project in Wisconsin. This project takes used wheelchairs destined for scrap and refurbishes them for additional use. In addition, this project provides a collective benefit for environmental protection, community services, assistance for disabled persons, and a venue for volunteer accomplishments. NCAI urges the Congress to support such noble concepts which provide mobility with dignity to temporary or permanently disabled Native Americans throughout Indian Country. Many tribal communities continue to suffer from a lack of adequate infrastructure, economic development and other community improvement factors necessary to properly administer their own welfare reform programs. In order to achieve these community development goals, tribes must have adequate funding for economic development, technical assistance, data collection, construction, job training, children and family support services, housing, transportation, alcohol and substance abuse programs and tribal enforcement plans. If federal support is not offered to help tribes create jobs, sustainable economies and community well being, welfare reform may lead to forced relocation, or even starvation, for many Native American families.

4. Administration on Aging

Three provisions under the purview of the Administration on Aging, authorized in the Older Americans Act (Pub. L. 89–73, as amended), are of special importance to Native American elders. The first is aging grants for Native Americans authorized in Title VI of the Older Americans Act. The purpose of this program is to promote the delivery of supportive services, including nutrition services, to older American Indians, Alaska Natives, and Native Hawaiians. NCAI requests that the full $30 million authorized for Title VI be appropriated in fiscal year 2000. Funding of this program provides key "front-line" services for 229 programs serving reservation elders, including congregate and home-delivered meals, transportation, and a wide variety of other services.

The second provision is Aging Research and Training, also authorized in Title IV. Activities supported under this program have helped organizations such as the National Indian Council On Aging (NICOA) gather knowledge about the problems and needs of Indian elders, and design and test innovative approaches to meet the needs of this rapidly-increasing population. Additionally, funds from this program have historically provided training funds for Title VI program directors. For fiscal year 2000, NCAI requests an appropriation of $630,000 with at least $130,000 earmarked for a continuing grant to NICOA to gather information on Indian elders and to quantify their needs. The remaining $500,000 should be directed to grants for training Title VI service providers to better serve Indian elders.

The third provision is Ombudsman/elder abuse prevention authorized in Title VII: Allotments for Vulnerable Elder Rights Protection Activities, Subtitle B: Native American Organization Provisions. Subtitle B was intended to assist in prioritizing elder rights issues and carrying out elder rights protection activities in Indian Country. With deteriorating economic and social conditions in many Indian communities, elder abuse is on the rise. Prevention programs for tribes are desperately needed—yet no funds have ever been provided for Subtitle B, despite an authorization level of $5 million. State programs currently receive $4.5 million for ombudsman services and $4.7 million for prevention of elder abuse programs. However, these programs seldom, if ever, reach Indian Country. Mr. Chairman, we request that the full $5 million be appropriated in fiscal year 2000 specifically for tribal programs as authorized in Subtitle B of Title VII.

During the coming year, Congress is expected to take action on a number of policy issues that will greatly impact Indian elders. Three of the more critical issues to be debated include reauthorization of the Older Americans Act (OAA) and the Indian Health Care Improvement Act; as well as the Administration's proposal to establish a National Family Caregiving Support Program, which has been included in Senator Daschle's bill, S. 10, to reauthorize the OAA. NCAI takes the following positions on these three issues.

First, the Older Americans Act was last reauthorized in 1992, with reauthorization long overdue. While appropriations for OAA programs can and do occur without reauthorization, programs serving Indian elders are at risk as the supply of discre-

tionary funds dwindle. For this reason, reauthorization without major changes to existing targeting language is critical.

Second, numerous provisions in the Indian Health Care Improvement Act will require significant modification to better serve Indian elders. When hearings are scheduled for this purpose, the NCAI would like to voice its suggestions for amendments.

Third, the Administration's proposal for assistance to family caregivers directs a large majority of the resources directly to states through the OAA. Unfortunately, as proposed, it does not direct any portion of these funds to Indian Country through the existing OAA mechanism—the Title VI program—or directly to tribes. When these issues are heard, the NCAI would welcome the opportunity to suggest ways to ensure that Indian caregivers can also receive adequate support.

Without exception, our tribal cultures teach us to honor and respect Indian elders so that our elders—the living expression of our heritage and highest values—can be teachers to us and to our children. We urge Congress to honor this mandate by providing adequate funding for those programs that impact Indian elders, to reauthorize the Older Americans and Indian Health Care Improvement Acts, and to ensure that Indian care givers are adequately recognized in any care giving assistance legislation.

5. Health Care Financing Administration

Indian Country has become increasingly aware of the impacts that major entitlement programs such as Medicaid, Medicare and the Children's Health Insurance Program (CHIP) have on their communities. Because of this, NCAI urges Congress to consider establishing direct tribal programs under the Health Care Financing Administration (HCFA), improve tribal access to existing HCFA programs, and mandate a significant increase in consultation between tribes and the HCFA over such program and service entitlements.

As highlighted above in our discussion on the IHS budget, a growing disparity exists between Indian and non-Indian citizens in per capita expenditures for Medicaid patients. We believe similar funding disparities exist for Medicare and are starting to emerge for the new CHIP program. In spite of these recent trends, recent statistics from the California Rural Indian Health Board and the Oneida Tribe of Wisconsin show a very low enrollment of American Indian and Alaska Native children in the CHIP program. The Balanced Budget Act of 1997, which created the CHIP program, and current HCFA consultation on the implementation of CHIP require state child health plans to prescribe procedures for the delivery of health care services to Indian children. As stated in NCAI Resolution #MRB–98–093 (attached), we must find ways to appropriately address the underlying reasons for these funding disparities and ensure that Indian people who are eligible for these programs can benefit from them. Moreover, Congress must focus on creating equitable funding streams from these important third party resources to the IHS/Tribal/Urban Indian (ITU's) health care entities that serve CHIP eligible Indian children.

There are a number of reasons that may help explain why these disparities exist and provide clues to how we might begin to overcome them. Many Indian people who would meet the eligibility criteria for these programs don't complete the application process, despite efforts by ITU's to encourage them to do so. For many, lack of transportation to distant eligibility offices, confusion about complex applications and documentation requirements, and inhospitable or culturally insensitive treatment by eligibility workers are barriers. These barriers could be overcome by providing funds for transportation and assistance with application and documentation processes and/or hiring and training more tribal members to serve as out-stationed eligibility workers in their own communities. These approaches would increase outreach, provide explanations of program requirements and benefits to tribal members, and assist applicants in navigating the eligibility determination process.

Certain financial requirements present more difficult barriers for Indian people in accessing these programs. Medicare requires payment of monthly premiums and certain deductibles and co-payments. While standard Medicaid programs do not require premiums, a number of Statewide Medicaid demonstration programs do impose premiums for some people; both standard and demonstration programs in some States impose co-payments for certain services. A number of State CHIP programs also impose premium and cost sharing requirements. Indian people receive IHS-funded services without such requirements in recognition of the Federal trust responsibility for the health, safety, and welfare of Indian people. To charge premiums or establish cost sharing mandates on the delivery of health care to Indian people is offensive and inconsistent with their belief that health care is a pre-paid treaty right.

Section 404 of the Indian Health Care Improvement Act (IHCIA) already offers a means to address most of these problems by authorizing grants and contracts with tribal organizations. While an earlier version of the law authorized several million dollars between fiscal year 1981 through fiscal year 1984, funds were never appropriated and the specific funding authorization amounts were later struck rather than continued. NCAI urges Congress to re-establish funding streams under the IHCIA as a cost-effective way to maximize third party coverage and collections.

Funding disparities arise not only from the difficulties ITU's face in enrolling Indian people in Medicare, Medicaid, and CHIP, but from other causes, including outdated limits for Medicare reimbursements for IHS and tribal health facilities. Other Medicare-covered services, such as those provided by freestanding clinics or by physicians and other practitioners have become increasingly important in Indian health, as in other health care systems, where there is increased emphasis on more cost-effective outpatient care. However, such services non-reimbursable to IHS clinics and physicians—a situation that Congress could easily be corrected this year in the reauthorization of the IHCIA. The growing prevalence of managed care in the U.S. health care system generally, and in Medicare, Medicaid, and CHIP, present special challenges for Indian people and the ITU's that serve them. Long before the term became popular in its current usage, Indian health programs were managing care. Due to widespread serious health conditions and limited funds, ITU's have long recognized and practiced early intervention, preventive care, case management, and pre-authorization of selective referrals for specialty care—all hallmarks of managed health care.

Despite their expertise in managing health care services and costs, ITU's find it difficult to fit into the emerging managed care networks that are becoming increasingly common in Medicare, Medicaid, CHIP, and the private health insurance industry. Such networks may be unfamiliar with, or unreceptive to, the special characteristics and needs of the Indian health system. Some managed care systems recruit and enroll Indian people but refuse to reimburse ITU's for covered services if the Indian person went directly to the ITU provider they have used for years, without going through the new managed care gatekeeper first. Case management is often done by a managed care organization, unfamiliar with Indian beneficiaries' medical history and cultural context. Reimbursement to ITU's, when is provided at all, is often inadequate to cover the cost of care.

The historic Balanced Budget Act of 1997 recognized some of these difficulties by exempting Indian people from the requirement that they be enrolled in the new Medicaid managed care State plan process unless there were an ITU participating in the process. However, the same protection was not extended to Medicaid managed care under the existing waiver processes, nor to managed care under Medicare or CHIP. Managed care is clearly the wave of the future. Exempting Indian people and health care providers may provide some short term relief, but in the long run, such an approach may simply produce the unintended result of leaving the Indian health system without the means to effectively participate and receive compensation from many public and private third party billing and collection systems.

We must look for innovative ways to build on the strengths of Indian health providers in managing culturally appropriate health care in ways that fit into emerging managed care networks. For example, Congress may examine the possibility of managed care organizations contracting with ITU's to perform gatekeeper and case management functions for Indian beneficiaries. Another option might be to explore the use of risk-adjusted reimbursement rates for ITU's as a way to cope with costly health care conditions connected with many of the beneficiaries they serve. In this way, cost overruns created from insufficient reimbursement rates developed on an average beneficiaries health care profile, a formula that does not account for extensive health care conditions, could be absorbed more easily. Congressional funding for research and demonstration projects like those eluded to above would be an appropriate way to begin addressing the concerns over health care delivery funding disparities in Indian Country.

Another primary reason for funding disparities may be the lack of long term care services in Indian Country. Long term care accounts for a large and growing part of Medicaid expenditures. There is a growing need for such services by Indian people; Indian elders are finally living long enough to need such care. However, providing needed long-term care to the elderly is growing increasingly complex. Relatives are increasingly unavailable to care for elders because they must work outside the home. IHS funding can only provide limited home health care through nurses and contract health representatives with no funding available for nursing homes or assisted living services, and tribally or privately operated nursing homes and assisted living facilities are scarce and costly to build and operate.

We are pleased that the President has chosen to focus more attention on long term care issues in recent years. However, proposals to date, such as the tax credit and long term care insurance, are likely to provide little help to meet the needs of the predominantly lower income population in Indian Country. We must have a comprehensive examination of the unmet needs and caregiving circumstances in order to develop appropriate, cost-effective solutions. The National Indian Council on Aging (NICOA) is beginning to develop such a study on long-term care in Indian Country. NCAI urges Congress to support such endeavors and use the knowledge gained from these studies to justify increased funding in the area of long-term health care programs for Indian people.

In order to reduce the disparities in health care spending we must address the barriers noted above and others yet to be identified. NCAI cannot do so alone. For that reason, we were encouraged to hear the DHHS Secretary and the HCFA Administrator, address the NCAI 1999 Executive Council Winter Session and pledge greater consultation with Indian Country as well as a commitment to act upon what they hear. We also look forward to the Secretary's invitation for tribal leaders to join in developing future DHHS budgets, beginning this Spring with the fiscal year 2001 budget process. We have participated in the development of recent IHS budgets and welcome the opportunity to extend this process to the rest of the Department. NCAI encourages Congress to direct all cabinet-level departments and their agencies within the federal government to increase tribal access to the development of future administrative budgets.

It is important to institutionalize mechanisms to make the government to government relationship real and enduring in meaningful ways. State and local governments and their representative organizations have long enjoyed recognition and procedures to facilitate their regular input into the policies, operations, and proposals of the Executive Branch. We request that DHHS address our current resolutions, including NCAI Resolution #MRB–98–037 (attached), which calls for Tribal consultation on proposed Medicare reforms; NCAI Resolution #MRB–98–093 (attached), which calls for use of a portion of national CHIP outreach funds to be used for Indian populations and having States provide copies of CHIP plans to tribes; NCAI Resolution #MRB–98–062A (attached), which opposes any Congressional reduction in Medicaid appropriations as part of any fiscal year budget resolution, and NCAI Resolution #GRB–98–046 (attached), which, among other things, calls for the DHHS to develop, with tribes, a plan that allows tribes to determine Medicaid eligibility for tribal member Medicaid beneficiaries.

We appreciate the DHHS issuing a consultation plan and DHHS staff efforts to begin consultation discussions. We are also encouraged by the HCFA regional office efforts on consultation with tribes in their states and in their willingness to facilitate some Tribal/State dialogues. In conjunction with NCAI Resolution #MRB–98–093 (attached), we are especially pleased with DHHS' plans to consult with tribes on the implementation of state CHIP plans and the state mandate to describe CHIP accessibility to eligible Indian children through HCFA regional office consultation this spring. We also need to extend consultation beyond regional tribal matters to develop a mechanism to address national policy concerns in a regular and timely way.

We appreciate the Administrator's recognition that it is important not just to listen but to do, to act on what is heard. In this regard, we are aware that HCFA provides resources to support regular national meetings with state Medicaid directors, as a whole, a smaller executive group, and through ongoing HCFA/State technical assistance groups that work on various issues. We would like to explore with HCFA how NCAI might jointly design a similar process for regular HCFA interaction with tribal governments to address the disparity issues noted above, as well as other emerging national policy issues of mutual concern.

Mr. Chairman, as previously stated to this Committee on May 21, 1998, during an oversight hearing on the unmet health care needs in Indian Country, NCAI urges Congress to fulfill its fiduciary duty to American Indians and Alaska Natives and to uphold the trust responsibility as well as preserve the government-to-government relationship, which includes the fulfillment of health care needs of all Indian tribes in the United States. This responsibility should never be compromised or diminished because of any Congressional agenda or party platform. Tribes throughout the nation relinquished their lands as well as their rights to liberty and property in exchange for these on-going services as well as this trust responsibility. Allowing tribal governments and their citizens a voice in determining the priority of meeting unmet health care needs in Indian Country is a positive step towards acknowledging the fulfillment of health care owed to all Indian tribes.

C. Department of Education

For fiscal year 2000, the Department of Education has requested $77 million of Indian education. This request will allow the Department's Office of Indian Education (OIE) to fund formula grants to Local Education Agencies (LEAs), restore certain discretionary funding for OIE and national research activities through the Department's National Center for Education Statistics (NCES). NCAI fully supports this funding for OIE as it promotes the President's education initiatives. The following are NCAI's recommendations regarding OIE funding by category:

1. Formula Grants to LEAs. For fiscal year 2000, $62 million is requested OIE's formula grant program to public schools. The Department estimates that this funding assists 461,000 Indian students attending public schools and over 5,000 students attending BIA schools for a total of 466,000.

2. Special Programs for Indian Children. NCIA fully endorses the Department's effort to restore discretionary funding for certain OIE programs. The $13.3 million request includes $3.3 million for the Special Programs for Indian Children and $10 million for a new American Indian Teacher Corps which would focus on the need to increase the number of qualified Indian teacher in the field. NCAI fully supports President Clinton's new centerpiece to recruit and train 1,000 new Indian teachers over a five year period who will then teach in schools with high concentrations of Indian students. Of the Nation's more than two million elementary and secondary teachers, less than one percent are American Indian or Alaska Native. The lack of role models has contributed to the disproportionately high drop out rates and low academic achievement rates of Indian students. Overall, the Special Programs account, if funded, would continue the following two initiatives: (1) demonstration grants for early childhood and preschool education; and (2) preparation of Indians to take positions in teaching and school administration.

3. Special Programs for Indian Adults. Since 1996, this program has received no funding. NCAI requests that $5 million be appropriated for this discretionary program devoted to increasing the educational skills of Indian adults.

4. National Activities. NCAI supports the Administration requests of $1.7 million to augment the Year 2000 National Center for Education Statistics (NCES) Schools and Staffing Survey (SASS) and other research initiatives. The data collection effort would ensure that American Indian students are included in upcoming NCES surveys that will yield additional information on American Indian learners.

5. Tribal College Executive Order. At the release of the Department's budget, no numbers were available for funding recommendations for the Tribal Colleges Executive Order which was funded in fiscal year 1998 at $200,000. NCAI has been informed by the Department that other agencies will have their resources combined for the order's implementation.

6. The National Advisory Council on Indian Education (NACIE). Over the past two years, NACIE has be funded at $50,000 to carry out its congressionally mandated role as a Departmental advisor for Indian Education. Although this funding allows for the two required meetings per year, the fifteen-member presidentially-appointed board has no permanent office and must rely on OIE staff to carry out minimal functions. NCAI is concerned that the Administration's request would neglect the inclusion of one of its own commissions, particularly in its obvious concern for Indian education. Therefore, NCAI request that $500,000 be appropriated for NACIE in light of their increased advisory role in the implementation of the Indian Education Executive Order signed by President Clinton in August, 1998.

7. OIE Fellowship Program. This program was last funded in fiscal year 1996 and represented a broad, non-targeted approach to ensuring Indian students participated in postsecondary education. At its peak, the program allowed approximately 150 Indian students annually to attend higher education institutions in fields as diverse as education to medical school. Although there has been increases in education funding, the American Indian higher education community has not been as fortunate. Complicating the situation is the fact that funding for higher education scholarships, at both the undergraduate and graduate levels through the Bureau of Indian Affairs and the Indian Health Service, have been cut over 50 percent since 1996. NCAI recommends that the fellowship program be funded at $5 million.

III. CONCLUSION

Mr. Chairman, we urge the Congress to fulfill its fiduciary duty to American Indians and Alaska Native people and to uphold the trust responsibility as well as preserve the Government-to-Government relationship, which includes the fulfillment of health, education and welfare needs of all Indian tribes in the United States. This responsibility should never be compromised or diminished because of any Congressional agenda or party platform. Tribes throughout the nation relinquished their

lands as well as their rights to liberty and property in exchange for this trust responsibility. The President's fiscal year 2000 budget request acknowledges the fiduciary duty owed to tribes. We ask that Congress maintain the federal trust responsibility to Indian Country and continue to aid tribes on our journey toward self-sufficiency. This concludes my statement. Thank you for allowing me to present for the record, on behalf of our member tribes, the National Congress of American Indians' initial comments regarding the President's fiscal year 2000 Budget.

PREPARED STATEMENT OF KATHYE GOROSH, PROJECT DIRECTOR, THE CORE CENTER

KEY ISSUES FOR HIV/AIDS

We are at a critical point in the care of patients with HIV/AIDS. We have achieved major goals in our basic science understanding of the course of HIV disease and have applied this understanding to the care of patients. Recent breakthroughs in drug therapies give reason to be hopeful for the successful treatment of HIV/AIDS.

Throughout the country, we have witnessed a steady decline in the number of hospital admissions for AIDS care and outpatient clinics are experiencing a dramatic increase in the demand for out-patient care and services. These successes have led to increased numbers of AIDS patients surviving longer and once again becoming productive members of society. Although science has taken big steps toward making AIDS a long-term manageable disease, by no means do we have a cure for the largest public health crisis of the century.

These favorable trends can be attributed in part to advances in opportunistic infection prevention and to highly active antiretroviral therapy (HAART). There are over 200 potent combinations of antiretroviral treatments that can be used in the fight against HIV/AIDS. For each of these different regimens and drug combinations, there is a wide variation in a patient's adherence.

With the hectic pace of the development and release of new drug treatments and care regimens for HIV/AIDS patients, it can be difficult even for specialty-care providers, and much more so for community-based care providers, to keep abreast of the most recent advances in care and medication usage. Without the ability to keep up with new drug developments, disease management is difficult, if not impossible, for community-based providers and patients.

While the technology exists to implement sophisticated education networks for HIV/AIDS, there is no successful system in place that provides caregivers and patients the education and scientific tools needed to ensure that they make the most of the advances in care.

Additionally, recent research has shown that the disproportionate incidence of HIV/AIDS among inner-city, minority populations is due in large part to low rates of adherence and lack of effective community-based, comprehensive, health education and training systems for providers and patients.

Lack of access to up-to-date information also hinders the ability of patients to fully understand the importance of adhering to their prescribed therapy. Unfortunately, incomplete adherence with medication regimens greatly increases the risk of the emergence of strains that are resistant to the newest therapies thus increasing the likelihood of the spread of HIV/AIDS.

Low rates of adherence can most often be attributed to the following:

1. *Cost*.—The cost for HAART therapy is enormous, as much as $10,000—$15,000 per patient per year. Although the federal program, AIDS Drug Assistance Program (ADAP), is designed to provide financial assistance for uninsured or underinsured HIV/AIDS patients in purchasing required medications, it has been unable to keep up with the increasing demands;

2. *Testing*.—Many individuals are still hesitant to be tested for HIV and often go without a diagnosis. As a result, patients go without care until the symptoms become evident and they are in need of immediate services. Delays in testing result in patients who are much sicker when they present for therapy.

3. *Education*.—Many HIV infected patients are unable to get timely clinical care or to adhere to complex and difficult drug regimens. Often patients have little or no understanding of newer therapies and their potential benefit, resulting in low levels of adherence and decreased health status.

Disparities among inner city, minority populations are also evident in the effectiveness of HAART therapies. While there have been dramatic new developments in HIV care due to these new and more powerful medications, including a 42 per-

cent decrease in the death rate from AIDS,[1] the outcomes have not been as positive for minority populations.

This disparity in opportunistic infection trends between population groups most reflects differences in access to the full range of new therapies now available. It is also indicative of a lack of targeted outreach, education and adherence enforcement efforts aimed at high risk populations and at those lifestyles which contribute significantly to the transmission of HIV.

The treatment of patients with HIV/AIDS in Chicago and other urban areas is made more difficult by the large number of patients receiving care and the large number of potential patients whose infections have not been diagnosed who will ultimately need care.

Specialists alone are not able to provide primary care for all affected patients, especially those in underserved communities. This means that other providers need to be trained in the complicated care of patients with HIV/AIDS to insure that the new HIV medications are used appropriately and to the greatest benefit for all patients.

To be effective, these community providers must have current medical data and protocols at their fingertips. They must be able to access immediate expertise to ensure the most accurate interventions and care for patients. Today, due to the lack of use of computerized clinical information systems in health care, especially for HIV/AIDS care, they are often unable to access this type of critical information or feedback in a timely fashion.

21ST CENTURY TECHNOLOGY FOR EDUCATION AS THE KEY

While many piecemeal technology based health education systems for HIV/AIDS exist throughout the United States, there are none that are taking full advantage of today's cutting-edge scientific landscape.

The adoption of computerized clinical information systems in health care lags behind the use of computers in most other sectors of the economy. There is no HIV educational system that provides care, clinical assistance and interactive education, while integrating the patients and community-based providers into the care giving and decision-making process. Especially given today's technological advances, this is a striking deficiency in health education systems for HIV/AIDS.

At this critical time in the evolution of the long-term treatment of HIV/AIDS, it is important that we focus on the creation and implementation of comprehensive provider and patient education and training systems. This focus will:

—Improve ability to manage disease and related conditions;
—Improve treatment and prevention efforts;
—Increase the rate of the early detection of HIV;
—Increase the rate of treatment adherence; and
—Decrease the spread of HIV.

The Department of Health and Human Services has recognized that effective education of providers and patients as well as adherence management programs are the only way to prevent those behaviors that lead to the spread of resistant strains of HIV. It is critical that the federal government continue to focus its resources on creating comprehensive HIV education and training systems that fully integrate specialists, community-based providers and patients and evaluate the outcomes of those systems.

The CORE Center believes that the most effective educational system is one which uses today's state-of-the-art technology and creates interactive networks of education that provide real-time feedback and enables providers to optimize care for HIV/AIDS patients.

Thus, the Center has proposed the Community and Minority Education and Training Initiative (COMET) for HIV/AIDS which maximizes the Center's extensive technological resources and care expertise to create and implement a unique, regional HIV/AIDS education and training network for HIV/AIDS providers and patients in community based settings, especially minority communities.

THE COMMUNITY AND MINORITY EDUCATION AND TRAINING INITIATIVE (COMET)

To address this significant health crises in the minority communities specifically, the African American community, The CORE Center in Chicago, Illinois, proposes the implementation of its "Community and Minority Education and Training (COMET) Initiative". Taking advantage of the new scientific landscape in the United States today, this initiative will demonstrate the significant improvements in care, prevention and education services through the use of a regional computer

[1] Centers for Disease Control HIV/AIDS Surveillance Report, June 1998.

network. COMET will expand upon existing technology at the CORE Center to provide computer assisted patient shared decision making and HIV/AIDS education, training and care feedback to providers and patients in the Chicago metropolitan area.

This demonstration project will create a national model of a technology-based education and training system for specialty and non-specialty, community-based HIV/AIDS care providers as well as the education of HIV/AIDS patients. It will address an existing national need in minority communities for the effective integration of educational programs to enhance provider performance and improve provider and patient ability to manage disease. It will improve patient response and adherence to treatment regimens and place emphasis on the incorporation of patients into a shared decision making process. Ultimately, this initiative will improve the quality of, and access to, care, increase adherence, and control cost.

The Community and Minority Education and Training Initiative will result in several key outcomes including:

—Improve non-specialist and patient access to the most current information on HIV/AIDS care, treatment, and drug protocols
—Provide critical and, as of yet non-existing, access to immediate feedback for providers to proposed patient care regimens
—Facilitate the supervised integration of community-based providers into the care of HIV/AIDS—thus expanding patient access to care for HIV/AIDS
—Provide a model for computer assisted patient shared decision making
—Improve physician's and patient's ability to manage HIV/AIDS and related infectious diseases.
—Improve patient adherence to complex care regimens
—Improve surveillance and response efforts at the local, state and federal levels
—Increase providers' ability to identify population specific treatment and care issues
—Reduce the emergence of additional resistant strains of HIV/AIDS
—Provide nationally relevant outcomes data that will be useful to cities across the United States as they grapple with issues of access, adherence, and cost and quality of care.

Through the implementation of a community-wide HIV education and training network, this initiative will provide nationally relevant outcomes data which will be useful to cities across the United States as they grapple with issues of access, adherence, and cost and quality of care.

The CORE Center, with its location in the heart of an inner-city, minority neighborhood, its single-site location for comprehensive HIV outpatient services, screening clinic, and its state-of-the-art information system, is uniquely positioned to implement this technology-based provider and patient education initiative. Additionally, because the Center's population is predominately African American and Latino, it will provide a unique model for improving the quality, efficacy and cost of care for minority populations through the use of a technology based education system for providers and patients of HIV/AIDS care.

Project COMET will demonstrate the efficacy of the technology-based education and training system in the following areas:

1. *Education*.—Demonstrate the ability of a technology based educational system (or distance learning system) to update and educate specialty and community-based providers and to educate and involve patients in a shared decision-making process.

2. *Early Intervention*.—Demonstrate the effect of a technology based educational system on the ability of the community-based and specialty care providers to target HIV screening of inner-city populations with sexually transmitted diseases (STDs), so that advances in HIV care will be made available as early as possible in the course of HIV disease and prevent risky behaviors that result in the spread of the HIV and related infectious diseases;

3. *Adherence*.—Demonstrate the ability of the system to enable non-specialty and community-based care providers to implement an aggressive adherence program to ensure the application of sound treatment principles and protocols, medication adherence and clinical follow-up of inner-city, minority patients; and

4. *Outcomes Research*.—Collect and analyze data to measure patient outcomes, the cost of care by different specialty and community-based providers as well as patient and provider adherence. In addition, this initiative will disseminate these findings.

The CORE Center is seeking $6.9 million in federal funding to implement this nationally significant initiative that will thoroughly examine the effectiveness of a technology based educational system on the improvement of care and treatment of HIV/AIDS. The Center believes that federal funding would be beneficial not only to the federal government but to cities across the nation as they grapple with this very

complex issue. COMET will complement federal efforts to develop HIV/AIDS policy in areas of treatment and information deficiencies, especially as they relate to the epidemic in minority, inner-city communities.

PREPARED STATEMENT OF THE UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY

The following is the testimony of the University of Medicine and Dentistry of New Jersey (UMDNJ), the largest public health sciences university in the nation. The UMDNJ statewide system is located on five academic campuses and consists of 3 medical schools, and schools of dentistry, nursing, health related professions, public health and graduate biomedical sciences. UMDNJ also comprises a University-owned acute care hospital, three core teaching hospitals, an integrated behavioral health care delivery system, a statewide system for managed care and affiliations with more than 100 health care and educational institutions statewide. No other institution in the nation possesses the resources which match our scope in higher education, health care delivery, research and community service initiatives with state, federal and local entities.

We appreciate this opportunity to bring to your attention the priority projects of UMDNJ that are consistent with the mission of this committee. These include a Child Health Institute; a Neurological Institute; geriatric initiatives and our efforts to combat threats of bioterrorism.

The Child Health Institute of New Jersey is located at UMDNJ-Robert Wood Johnson Medical School (RWJMS) in New Brunswick, New Jersey. As part of the state's public higher education system, the medical school's 2,500 full-time and volunteer faculty train about 1,500 students in medicine, public health and graduate programs and ranks in the top one-third of the country with regard to the percentage of its students who practice in primary care specialties after completing their residency training. The School ranks in the top one-third in the nation in terms of grant support per faculty member. RWJMS is also home to The Cancer Institute of New Jersey, the only NCI-designated clinical cancer center in New Jersey; The Center for Advanced Biotechnology and Medicine; and the Environmental and Occupational Health Sciences Institute, the largest environmental institute in the world.

The Child Health Institute is a comprehensive biomedical research center focused on the health and wellness of children. In this program, medical researchers direct efforts toward the prevention and cure of environmental, genetic and cellular diseases of infants and children. The Institute is integral to the long-term plan for the enhancement of research at the medical school in developmental genetics, particularly as it relates to disorders that affect a child's development and growth, both physically and cognitively.

The program will enable the medical school to expand and strengthen basic research efforts with clinical departments at the Robert Wood Johnson University Hospital and with the new Children's Hospital in the areas of Obstetrics, Pediatrics, Neurology, Surgery and Psychiatry. The Child Health Institute will fill a critical gap in services through the recruitment of an intellectual base upon which basic molecular programs in child development will build.

The Child Health Institute will focus research on the molecular and genetic mechanisms which direct the development of human form, subsequent growth, and acquisition of function. Broadly, faculty and students will investigate disorders that occur during the process of development to discover and study the genes contributing to developmental disabilities and childhood diseases; to determine how genes and the environment interact to cause childhood diseases; and to identify the causes and possible avenues of treatment of cognitive disorders broadly found among conditions such as mental retardation, autism and related neurological disorders.

Despite effective therapy, asthma related health needs have risen by almost 50 percent over the past decade with hospitalization rates 4 to 5 times higher for African Americans. Methods of prevention have only been partially effective. Treatments with regimens are relatively unchanged. Effective prevention and treatment will require more understanding of the molecular mechanisms of the stimuli-receptor reactions that elicit asthmatic attacks as well as more detailed understanding of the molecular reactions effected by cells once stimulated by environmental factors. The molecular and cellular basis of injury reactions, including reactions of an allergic nature, will be a focus of the research of the Child Health Institute. Injury reactions are central to diseases of many different etiologies, yet have come to be understood to be involved in clinical problems broadly from asthma to atherosclerosis. Continued exploration of the basic molecular underpinnings of injury reactions will lead to more rational methods to prevent, minimize and treat asthmatic

reactions and deaths. Urban academic medical centers are at the epicenter of the current escalation in asthma and the Child Health Institute is well positioned to address this critical issue.

The CHI builds on existing significant strengths within RWJMS and our associated joint research institutes with Rutgers University. The CHI will act as a magnet for additional growth in research and health care program development in New Jersey. Fourteen senior faculty will direct teams of M.D. and Ph.D. researchers, visiting scientists, postdoctoral fellows, graduate students and technicians for a full complement of some 130 employees. At maturity, the Institute is expected to attract $7 to $9 million dollars of new research funding annually. The Institute has already received a $5.9 million grant from the Robert Wood Johnson Foundation, one of the largest philanthropic foundations in the world, and $5.9 million from Johnson & Johnson, the world's largest manufacturer of health care products.

We respectfully request $2 million for targeted program assistance for the Child Health Institute of New Jersey.

The Neurological Institute of New Jersey was established by the UMDNJ-New Jersey Medical School and UMDNJ-University Hospital, both based in Newark, New Jersey, as a center of excellence in the neurosciences in recognition of the fact that neurological diseases are a leading cause of death and disability and the widespread expertise that exists in this discipline on our Newark campus. No other entity in New Jersey approaches the depth of human expertise, technological advancements and research achievements that currently exist in the wide variety of services at the medical school and the hospital.

UMDNJ-University Hospital is the major provider of tertiary neurological and neurosurgical services to the State of New Jersey, including patient care, education and research. The NJMS Department of Neurosciences ranks sixth nationally in research funding with $4 million annually. NJMS offers the only fully accredited neurosurgical residency program in the state.

The Neurological Institute would serve as an umbrella under which clinical, research and educational efforts would be focused. The delivery of clinical care would be provided through University Hospital, its clinics, physician offices and affiliates. Education would be provided by multidisciplinary teams focused on neurological disease including prevention, early diagnosis, treatment and rehabilitation. The Institute would collaborate with its regional academic affiliates, the New Jersey Institute of Technology and Rutgers-Newark in promoting research.

Neurological disorders, including stroke, epilepsy, multiple sclerosis and Alzheimer's disease are common and debilitating. Nationally, neurological disorders are one of the leading causes of death and disability. Fifty million Americans are affected by these diseases and there are five million new cases diagnosed yearly. Neurological diseases account for about $400 billion in health care costs and lost productivity.

While the devastation of neurological disease and injury can be horrific, amazing breakthroughs in treatment and new drugs or surgical techniques are occurring. These breakthroughs require painstaking research and testing, significant financial support, and a concentration of clinical expertise and potential research subjects in a controlled environment. Unfortunately, the lack of such a statewide focus in the neurosciences has limited New Jersey's participation in and access to leading edge research, clinical trials and beta-site technology. The Neurological Institute will allow New Jersey to establish the credentials and clinical material necessary to compete for the advanced basic science and clinical research projects that currently are out of reach. Also, the critical mass of expertise provided by the Institute will hasten the pace at which theories become therapies in New Jersey through its educational opportunities and sponsorship of new technology at its clinical sites.

We respectfully request $1 million for operational, research and treatment advances for the Neurological Institute of New Jersey.

The Center for Aging at UMDNJ-School of Osteopathic Medicine in Stratford, New Jersey is a multi-disciplinary, multi-departmental center of excellence in clinical services, education and research committed to meeting the diverse health care needs of an aging population. The Center's emphasis on wellness and health promotion encourages patients to improve or maintain their health and their independence. The Center is in a unique position to assume the leadership of a statewide Institute on Aging and Interdisciplinary Practice to serve the growing numbers of elderly in the state and the health care professionals who provide care to this population.

The Center for Aging has educated more than 7,500 health care professionals from multiple disciplines on caring for elderly individuals. Creation of a statewide Institute will permit the Center to provide leadership and share its expertise in the development of an array of services and programs that will enhance the knowledge

of health care providers, form new partnerships in the delivery of high quality geriatric care, and promote research on models of interdisciplinary practice and care management which will benefit New Jersey's senior citizens.

The Center administers a variety of innovative health care programs developed in response to the shift from hospital care to ambulatory or outpatient treatment. As the southern New Jersey site for evaluation of Alzheimer's Disease, the School of Osteopathic Medicine provides a comprehensive program for the evaluation of dementia. Conducted by the Center's multi-disciplinary team, the evaluation process includes medical, neurological, functional and psychosocial evaluation. Follow up care and monitoring is provided where needed. Elderly patients with multiple, complex health problems and needs receive comprehensive evaluations and are referred to existing community resources and referring physicians.

In addition to education and patient care, research is a vital component of the Center. The various geriatric services offer ideal opportunities to gather data on a diverse elderly population. Faculty, staff and students in the Center are actively engaged in clinical drug trials, research on aging-related health problems and other service-based projects as part of the Center's mission to improve care to the elderly and enrich educational experiences.

We respectfully request $2.5 million to expand and enrich our programs in geriatric education, research and patient care into a statewide network to serve New Jersey's aging population.

In our complex world of instant communication and ease of global transportation, disaffected individuals or political groups have access to highly destructive weapons of terror. With our open society the United States is particularly at risk to an individual with a grudge, a band of ideologically motivated fanatics, or to nations seeking revenge. The possibility of the employment of weapons of mass destruction on an innocent population has already become a reality with the Sarin nerve gas attack in the subways of Tokyo.

State and local governments and health organizations need reliable information upon which to develop and coordinate response plans for contingencies due to weapons of mass destruction. They need programs to educate planners and response teams on the public health aspects of these threats and how to recognize and respond to them. In addition, they need to understand both the short and long term implications for human and ecologic health. To develop such a plan requires a broad base of scientific and educational expertise. Scientific expertise is also needed to devise approaches for the early detection and treatment of biological and chemical weapons of terror.

As the nation's most densely populated state, we in New Jersey have a particular concern about being targets of bio- and chemo-terrorist activities. Our communities abut each other and our traffic patterns are statewide making us especially vulnerable to infectious disease. There are no obvious geographical boundaries to readily institute a quarantine. Our central location as a transportation hub for the populous Northeast also makes us a prime target.

There are three types of weapons available to them. For one, explosive devices, although increasingly deadly, our society has developed emergency response approaches to deal with, including explosions caused by sources as varied as factory processes and gas mains. The other two types of terrorist weapons are relatively new and present particular challenges to our normal response processes. These are chemical weapons of terror, such as nerve gas, and biological weapons of terror, such as anthrax bacillis. Chemical and biological weapons differ dramatically from explosions in that for these newer threats early recognition and diagnosis is crucial for both those initially affected and for others who might yet be affected through spread of infection or contact with the chemical.

Education of emergency responders to correctly identify these threats is crucial to minimize the impact of biological and chemical weapons, as well as to protecting the emergency responders themselves. Compounding our problems is the need for a better understanding of the effects of likely chemical and biological agents of terrorism, and of the means to prevent their spread and treat their victims.

The nation's foremost program in education and training concerning chemical and physical threats is headed by a UMDNJ faculty member, Dr. Audrey Gotsch, who is currently President of the American Public Health Association. Among her programs is the Center for Education and Training which provides training concerning chemical and physical agents to more than 160,000 police, firefighters, municipal and state employees, as well as to physicians, nurses and industrial hygienists.

Also, researchers at the Child Health Institute at the UMDNJ-Robert Wood Johnson Medical School in New Brunswick, New Jersey are looking into the effects of radiation on children in utero and on their growth and long-term development. Children who survive bioterrosist attacks live and carry forward the results of that at-

tack in a different manner than exposed adults. The basic mechanisms of biology that operate to cause serious neurological injury can be counteracted or reversed if properly understood at the molecular and chemical level.

Because of its scientific expertise, UMDNJ is uniquely qualified to develop a program to educate state and municipal governments, emergency responders and health and hospital professionals on planning for the response to terrorism; to train personnel to deal with threats of terrorism and how they affect public health; and to conduct research into the effects of chemical agents on the general population, with an emphasis on the long-term effect on children.

We respectfully seek $1.5 million through the Department of Labor/HHS/Education to expand our research, education and training programs in response to threats of chemical and biological terrorism.

PREPARED STATEMENT OF THE COALITION FOR AMERICAN TRAUMA CARE

The Coalition for American Trauma Care is pleased to provide testimony on the importance of supporting injury prevention and trauma care activities across the U.S. Public Health Service.

The Coalition's membership consists of leading trauma center institutions, leading trauma clinicians, and 15 national organizations including the American Association for the Surgery of Trauma, the Eastern Association for the Surgery of Trauma, the Orthopaedic Trauma Association and the American Burn Association. The mission of the Coalition is to improve trauma and burn care through improved care delivery systems, prevention efforts, and research.

Increased attention in recent years to the problem of injury has been greatly needed. Injury is one of the most important public health problems facing the United States today. It is the leading cause of death for Americans from age 1 through age 44. More than 145,000 people die each year from injury, 88,000 from unintentional injury such as car crashes, fires, and falls, and 56,000 from violence-related causes. Over 85 children and young adults die from injuries in the U.S. every day translating into 30,000 deaths annually. Injury is also the most frequent cause of disability. Millions of Americans are non-fatally injured each year leaving many temporarily disabled and some permanently disabled with severe head, spinal cord, and extremity injuries. Because injury so often strikes the young, injury is also the leading cause of years of lost work productivity and, at an estimated $224 billion in lifetime costs each year, trauma is our nation's most costly disease.

With this as background, the Coalition makes the following recommendations regarding funding for injury prevention and trauma and burn care activities in fiscal year 2000:

Trauma and Emergency Medical Services Systems.—Last year, Congress reauthorized the Trauma Care Systems Planning and Development Act for three years and specified that $6 million should be provided to stimulate further progress in trauma and emergency medical service system development across the nation, but particularly in rural areas. The Coalition supports this funding level for fiscal year 2000. The legislation calls for matching funds from the states as follows: 100 percent federal in year one; 1:1 in year two; 1:3 in year three. This program, administered by the Health Resources and Services Administration, was originally enacted in 1991 and was funded for three full years at approximately $5 million. The program was reauthorized in 1994 for another three years, but its fiscal year 1995 funding was rescinded and no funding was provided in fiscal year 1996 causing the demise of the program. Under the program, nearly 40 states received at least one year of funding. Many used funds to initiate trauma systems development, but were unable to proceed with full implementation due to the loss of funding.

Attached to my testimony is a "quick and dirty" survey of states conducted by the National Association of State EMS Directors on May 30, 1997 to assess how the HRSA administered program, known as the Division of Trauma and Emergency Medical Services (DTEMS), had impacted state trauma system development. As you can see, of the 43 states responding, 30 had received DTEMS funding and fully 28 reported that the loss of the DTEMS funding hurt their efforts at trauma system development. Five states reported that the DTEMS program helped to initiate their trauma system, and now have fully functional systems. Another 18 states reported they had started their trauma system development with DTEMS funding, but could not finish the job. Fully 26 states reported that they do not have any state funding for trauma system development.

Why is this important? Numerous studies have shown, over the years, that organized systems of trauma care dramatically lower the number of preventable deaths resulting from serious injury. Some studies, for instance, have shown that prevent-

able death rates can drop as much as 50 percent the first year a trauma system is implemented, and can be lowered to under 5 percent in years thereafter. These findings were noted in a 1985 General Accounting Report which recommended federal leadership to support the development of trauma care systems. The important impact of trauma systems in saving lives was also noted in a report issued last November by the Institute of Medicine entitled, Reducing the Burden of Injury. One of the recommendations of the IOM panel is as follows:

"The Committee supports a greater national commitment to, and support of, trauma care systems at the federal, state and local levels and recommends the reauthorization of trauma care systems planning, development, and outcomes research at the Health Resources and Services Administration."

Congress has already accomplished that legislative step of reauthorization. The trauma and emergency medical services community now urges you to provide the funding resources necessary to finish the job of trauma and emergency medical services system development in every state. Until every state has adequate emergency medical services and trauma care systems, particularly states with large rural areas, we must continue to provide federal leadership. Until that job is done, it means that an American family driving across the country this summer to visit our national parks and other attractions will experience a 50 percent difference in their chance of surviving a serious crash every time they cross a state line.

National Institutes of Health.—The Coalition for American Trauma Care supports the Ad Hoc Group for Medical Research Funding's recommendation of a 15 percent increase in funding for the NIH for fiscal year 1900. However, the Coalition is very concerned that as much of the increase as possible come from funds that are in addition to the currently tightly capped discretionary accounts. While the Coalition believes the National Institutes of Health can effectively use significant increases in funding, these increases should not come at the expense of other critical public health programs.

The Institute of Medicine's November, 1998 report, Reducing the Burden of Injury, makes the following recommendation with regard to the National Institutes of Health:

"The Committee supports a greater focus on trauma research and training at the National Institutes of Health and recommends that the National Institute of General Medical Sciences (NIGMS) elevate its existing trauma and burn program to the level of a division. To accomplish this goal, the Committee recommends the expansion of research and training grants and the formation of an NIH-wide mechanism for sharing injury research information and for promoting collaborations spearheaded by NIGMS."

As the IOM report delineates, NIH spends less than one percent of its overall resources for injury-related research despite the enormous public health impact of injury in the U.S. The Coalition supports the IOM Injury Committee's findings and recommendations with regard to the NIH and urges the Subcommittee to include report language in the fiscal year 2000 Labor-HHS-Education Appropriations bill which restates the IOM's recommendation.

The Coalition also supports an increased emphasis within the NIH on clinical research so that the benefits of basic science efforts can reach the bedside.

Other funding recommendations the Coalition for American Trauma Care Supports for fiscal year 2000:

National Center for Injury Prevention and Control.—The Centers for Disease Control and Prevention has developed a new five year initiative called "SAFE AMERICA . . . . Through Injury Control." The program is designed to implement in states and local communities those injury control strategies that have been tested over the past several years by the National Center for Injury Prevention and Control and proven to be successful. The Coalition urges you to provide $20 million funding for this life saving program. Within the Safe America initiative, the Coalition has particular interest in funding for trauma systems research. NCIPC has initiated a three year grant program to study trauma outcomes. The Coalition recommends continued funding of this research effort at a level of $2 million for fiscal year 2000. The Coalition also seeks funding support within the Safe America initiative for implementing smoke detector programs which CDC research demonstrates reduces burn-related injuries, and bicycle helmet use efforts to help prevent the 20,000 head injuries that occur every year.

Preventive Health/Health Services Block Grant (PHHS).—The Coalition urges you to provide $182 million in funding in fiscal year 2000 for this program which is the largest source of federal funding for state Emergency Medical Services (EMS)—the first line of defense against death and disability resulting from severe injury. This program has sustained cuts in funding over the past several years. Every time the

block grant has been reduced EMS funding has dropped precipitously. In 1981 EMS funding was $30 million; it is now under $10 million for the 50 states.

The Agency for Health Care Policy and Research (AHCPR).—The Agency for Health Care Policy and Research is the only federal agency devoted to assessing the most cost-effective use of the health tax dollar. AHCPR is an important source of funding to assess trauma and burn services research so that emergency response and treatment approaches to the very costly problem of serious injury are as efficient and cost-effective as possible. Trauma and burn clinicians are constantly challenged to find ways to cut costs in the current managed care environment, but want to do it correctly by maintaining, or improving, quality of care and patient outcomes. Accomplishing this goal requires a specific research investment that can only be undertaken by the AHCPR with an increase in funding for this essential agency. The Coalition urges you to provide $225 million in fiscal year 2000 funding so that the AHCPR can continue its widely praised Medical Expenditure Panel Survey and also fund continuing, and most importantly, new critical quality of care research.

Children's Emergency Medical Services.—Injury is the leading cause of death for children in the U.S. The Children's EMSC program at the Health Resources and Services Administration is designed to improve the emergency response to children who are critically injured or ill. The Coalition urges you to provide $17 million in fiscal year 2000 appropriations for this vital program.

Traumatic Brain Injury.—Traumatic brain injury is a leading cause of trauma-related disability. Brain injury is a silent epidemic that compounds every year, but about which still little is known. The Coalition urges you to provide $15 million in fiscal year 2000 appropriations to fully fund the Traumatic Brain Injury Act, which is in the process of reauthorization, as follows: $5 million for CDC for surveillance so that we can learn the incidence and prevalence of brain injury in the U.S. population and $7.5 million for HRSA grants to states for demonstration projects to improve access to health care and other services and $2.5 million for special research projects at the National Institutes of Health.

The Coalition for American Trauma Care appreciates the support the Subcommittee has provided to many trauma and burn related programs in the past. However, much remains to be done to address this leading public health problem so that we can achieve the substantial health and social welfare cost savings addressing increased research, timely treatment and rehabilitative interventions, and prevention will provide the citizens of the United States. The Coalition looks forward to working with you to achieve these goals.

NATIONAL ASSOCIATION OF EMS DIRECTORS SURVEY OF IMPACT OF FEDERAL LEGISLATION ON STATE TRAUMA SYSTEMS

Survey sent out May 30, 1997—43 States responded

1.	We received DTEMS funding	30
	We did not receive DTEMS money	13
2.	Our trauma system was in place already before DTEMS	13
	We started our system with DTEMS dollars, but could not finish it	18
	We started our system with DTEMS dollars, and have functional system now	5
	Not applicable, no response, have done nothing	
3.	We have a trauma plan written, but not implemented	14
	We have statutory authority and have designated facilities (some/all)	19
	We have statutory authority, but have NOT designated facilities	4
	Not applicable, have no system plans	5
4.	We have state funding dedicated to our trauma system	16
	We do not have state funding	26
	No answer	1
5.	The loss of the DTEMS program hurt our efforts	28
	Did not hurt our efforts	13
	No answer	2

PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the Subcommittee with a statement recommending fiscal year 2000 funding levels for the agencies and programs of the Public Health Service. The Coalition is a nearly thirty year old alliance of 40 national health associations with a combined membership of 40 million health care professionals, researchers, lay volunteers, patients and families. The Coalition

is dedicated to working with Congress, in a non-partisan fashion, on behalf of federal health discretionary programs, primarily the agencies and programs within the Public Health Service. It is the oldest, most broadly based coalition focused on the breadth of discretionary health spending.

The Coalition sincerely appreciates the strong and continued support that the Subcommittee has given to health discretionary programs.

This year, the Coalition's recommendations, and the work of this Subcommittee, have special significance as we prepare the nation to respond to the public health challenges in the first year of the next millennium. The health of the American people, now and into the twenty-first century, is certainly one of the nation's most valuable resources—could we even begin to calculate the value of America's public health? The pennies we invest in public health today will reap billions of dollars of future returns. Of the thirty years of American life expectancy added this century, fully 25 years are due to public health interventions, including control of infectious diseases, and improvements in nutrition, sanitation, and occupational safety. In the coming century, we expect our continued investments in public health to yield equally remarkable returns.

But we also face serious challenges in public health in the new century. First, the global economy places us at increased risk for new and emerging infectious diseases. Second, bioterrorism and other potential threats to significant numbers of Americans will require major investments in the country's public health infrastructure to ensure that when and where the public's health is threatened, we have the resources to respond quickly and effectively at the local, state and national levels. Third, chronic disease continues to claim the health and productivity of too many Americans too early in their lives. Fourth, access to medical care, particularly preventive care and early intervention, is still lacking for far too many Americans who live in rural and inner city areas.

These are the major challenges ahead in the 21st Century. To address them and reap the potential of enormous positive returns requires adequate investment across the continuum of public health activity. We must simultaneously support basic biomedical, behavioral and health services research, community-based prevention efforts, targeted service delivery for vulnerable and medically underserved populations, and education of a health professions workforce. The coalition's members recognize the interdependency of these goals and that no one component of the public health continuum can be effective without the strong support of the others.

I would like to provide you with just a few examples of this—how our investment in the research that is conducted at the National Institutes of Health, for example, leads to improved health outcomes through our investment in the other public health agencies and activities.

SIDS is the leading cause of death for infants under one year of age, however, deaths due to SIDS have fallen by more than 38 percent as a direct result of the National Institutes of Health (NIH) research advances working in partnership with other public health agencies and the private sector. Meta-analyses of SIDS studies revealed the role of sleeping position in infant deaths. NIH initiated the "Back to Sleep Campaign," an educational effort that encourages parents and other care givers to place infants on their backs to sleep to reduce the risk of SIDS. Working with the private sector, and through the Maternal and Child Health Block Grant administered by the Health Resources and Services Administration (HRSA), this research has reached parents of all socioeconomic levels and has resulted in a dramatic reduction in SIDS deaths. However, we also know that further outreach is needed and necessary to get this message out to minority group communities as well as to child care centers.

We now know, due to research conducted by the NIH, that if all American women consumed 400 mcg of the B vitamin folic acid each day, 50–70 percent of all cases of spina bifida and anencephaly would be prevented, saving about $245 million per year. The Centers for Disease Control is conducting a national public awareness effort to educate women of child bearing age to consume enough Vitamin B folic acid through foods and, as necessary, through vitamin supplements.

We look to NIH-sponsored research to help develop drugs to successfully treat those with HIV/AIDS, but we look to HRSA's Ryan White program to make the drugs affordable and available to those who are infected, but who can't afford care.

In the area of chronic disease, our investment in NIH research has identified a limited number of unhealthy lifestyle behaviors, many adopted in early life, which contribute to hundreds of billions of dollars in direct and indirect cost due to heart disease, cancers, diabetes, and intentional and unintentional injuries. Investing in nationwide disease prevention and health promotion activities to reduce this largely preventable national burden will more than pay its way. Many areas of the public

health service are engaged in this important effort: CDC, AHCPR, HRSA, and Office of Public Health and Science among others.

The Coalition for Health Funding appreciates the difficult budget constraints facing the Subcommittee, but believes the relatively small proportion of federal funding now spent on public health is an important investment in the future because it will ultimately save billions of dollars. As a proportion of overall health expenditures, federal public health activities account for $29 billion—three percent—of the estimated $1 trillion spent on health care in the United States. It is critically important, as we balance the federal budget, that we are not penny wise and pound foolish and that our successes over the past 200 years continue into the next millennium.

Each year the Coalition for Health Funding works with other national health alliances to determine an appropriate level of federal support for all health discretionary programs. For fiscal year 2000 the Coalition is recommending $34 billion be provided to address the nation's needs in the areas of biomedical, behavioral, and health services research; disease prevention and health promotion; health services for vulnerable and medically underserved populations; health professions education; and substance abuse and mental health services. The Coalition's recommendation also includes funding for the Indian Health Service and the Food and Drug Administration, which are not within the jurisdiction of this Subcommittee, but are important agencies within the U.S. Public Health Service. The Coalition appreciates that these funding levels may appear excessive, but they reflect both the professional judgment within the various agencies as well as our own members' assessment of community need. The Coalition presents these recommended funding levels to the Subcommittee in the hope that it will view them as important targets for optimal health outcomes.

The following is a partial list of the Coalition's findings and recommendations; the attached table provides the Coalition's recommendations for all the public health agencies:

National Institutes of Health (NIH)

[In billions of dollars]

Fiscal year 1999 appropriation	15.652
President's fiscal year 2000 request	15.972
CHF fiscal year 2000 recommendation	18.000

The Coalition for Health Funding recommends a fiscal year 1900 funding level of $18 billion for NIH, but wishes to express the strong caution that this increase must not come at the expense of other public health programs. This increase is $2 billion (12.6 percent) more than the President's request and $2.3 billion (15 percent) more than fiscal year 1999 funding.

The Coalition supports the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in funding for the National Institute of Health (NIH) in fiscal year 2000 as the next step toward doubling the NIH budget by 2003. But in recognition of the difficulty in achieving this goal under the current spending limits, the Coalition cautions that this increase must not come at the expense of other public health programs. Moreover, we urge Congress to explore all possible options to identify the additional resources needed to support this increase.

The Coalition recognizes the critical importance of the research conducted at the NIH and that increases provided in fiscal year 1999 must be significantly continued in order to reap our investment. Volatility and dramatic fluctuations in funding can be as harmful to the research enterprise as inadequate growth. We risk wasting the investment that has been made this year if scientists do not have the resources in future years to continue the work begun with fiscal year 1999 funds. The President's fiscal year 2000 request of $320 million over the fiscal year 1999 funding level clearly jeopardizes our the progress we are making in medical research.

The Coalition also supports the Ad Hoc Group for Medical Research Funding's statement that medical research is the foundation underlying a continuum of public health programs and activities that include health services and outcomes research, health care delivery to underserved populations, health professions education, and disease and injury prevention. The Ad Hoc Group states that without these essential public health partners, we will fail to achieve the goal of a healthier, more productive nation.

Centers for Disease Control and Prevention (CDC)

[In billions of dollars]

Fiscal year 1999 appropriation	2.9

Centers for Disease Control and Prevention (CDC)—Continued

Fiscal year 2000 President's request	3.1
CHF fiscal year 2000 recommendation	3.9

The Coalition for Health Funding recommends an overall funding level of $3.9 billion for the CDC in fiscal year 2000. This is $800 million (25 percent) more than the President's request and $1 billion (34 percent) more than fiscal year 1999, reflecting the need to make prevention efforts even more of a national priority.

The Coalition is very pleased that Congress provided $124 million in fiscal year 1999 to begin the process of re-building the nation's seriously eroded public health infrastructure in order to prepare for bioterrorism. That infrastructure includes epidemiologic surveillance and response capacity, laboratory capacity, and electronic communication capability at the local, state, and federal levels of government, but particularly local and state. The President has proposed continued infrastructure funding, but the needs are much greater than his budget request of $138 million ($118 m plus $20 million in new monies provided to the Infectious Disease Program). The Coalition supports $263.5 million in funding in fiscal year 2000 to truly address the gaps in our public health system, and supports another $25 million to build a national electronic surveillance system—our first line of defense against a bioterrorist attack.

Building public health infrastructure will not only help to prepare the nation for a bioterrorist attack involving agents, such as anthrax and smallpox, but will also reap rewards—every day—because it will be used—every day—to much more fully address food safety concerns, naturally occurring infectious diseases, environmental hazards, and even help us discern patterns of chronic disease and injury that will help us design effective prevention strategies.

The Coalition is pleased that the President requests increased funds for polio and measles eradication, but does not provide any increases for the Section 317 childhood immunization program—funding for state and local infrastructure such as actual program delivery, outreach efforts, and registry implementation. During 1998, grants to states were cut by as much as 30 percent. These deep cuts may eventually cause a reversal in the successful immunization coverage rates for pre-school children of nearly 80 percent achieved in 1996.

Sufficient funding is provided under the Coalition's recommendation to permit the National STD-Related Infertility Prevention Program to be extended from the current minority of states to the rest of the nation. This program provides chlamydia screening and treatment to women attending family planning and STD clinics, plus their partners, in four U.S. Public Health Service regions. The Coalition's recommendation would also support the increased funding for HIV/AIDS prevention which is clearly needed since the epidemic is still spreading in the United States. It also provides sufficient funding for the continued efforts of the TB program.

For chronic disease programs, the Coalition's fiscal year 1900 recommendation would permit the Breast and Cervical Cancer Program to be extended to every state. This program supports state health departments in building a national infrastructure to provide education, screening, follow-up and test quality assurance for breast and cervical cancer. Early detection and follow-up could prevent virtually all cervical cancer deaths and more than 30 percent of breast cancer deaths. Delayed detection also increases health care costs: from as low as $13,800 for cases detected early to as much as $84,000 for advanced cases. The Coalition's fiscal year 2000 recommendation for CDC would assist in extending the Diabetes Translation Program to every state. Diabetes is the seventh leading cause of death in the U.S. It is estimated that at least half of the 13,300 new cases of diabetes related end-stage renal disease could be prevented, saving approximately $240 million annually. Every state needs the cost-effective services of the Diabetes Translation Program. The Coalition's recommendation would also permit increased funding for a multifaceted approach to cardiovascular disease (CVD) prevention designed to reduce the prevalence of risk behaviors. CVD is the leading killer in the U.S. for both men and women across all ethnic groups.

The Coalition's fiscal year 2000 recommendation would permit $182 million in funding for the Preventive Health/Health Services Block Grant. This level of funding is the minimum amount states have identified they need to meet the Healthy People 2000 goals they have committed to achieving. The PHHS Block Grant is the only flexible funding source for states to fill the gaps for specific health needs for their populations. The Coalition is very disappointed with the President's request for a $30 million cut in this vital, prevention program that many state health officials consider one of their highest funding priorities.

Health Resources and Services Administration

[In billions of dollars]

Fiscal year 1999 appropriation	4.1
Fiscal year 2000 President's request	4.2
CHF fiscal year 2000 recommendation	4.9

The Coalition for Health Funding recommends an overall funding level of $4.9 billion for HRSA in fiscal year 2000. This funding level is $700 million (17 percent) more than the President's request and $800 million (19 percent) more than fiscal year 1999.

This requested funding level would permit the health cluster of programs (i.e., community, migrant, homeless and public housing) to continue services to over 10 million low-income people in all 50 states, as well as allow health centers to extend services to an additional 300,000 low-income, uninsured people.

The President's fiscal year 2000 budget request zeros out funding for two of the health professions clusters created under the newly reauthorized Title VII and Title VIII Health Professions and Nursing Education programs. These clusters include primary care and general dentistry and public health and preventive medicine. It seems illogical for the President to take this action after signing legislation reauthorizing a newly streamlined program. The Coalition supports a funding level—$316 million—that will provide a small increase, not decrease, for both the Title VII Health Professions and Title VII, Nursing Education programs. These important programs help ensure that those living in medically underserved areas of our nation have access to health care services.

The Coalition's fiscal year 2000 recommendation includes increased funding the Title V Maternal and Child Health Block Grant to ensure that the Child Health Insurance Program (CHIP) is fully utilized by those children and adolescents who are eligible by permitting critical outreach efforts. This increase would also enable expansion of cost-effective programs for low-income working families such as those providing prenatal care, newborn screening, home visiting and well-child care for over 18 million pregnant women, children, and children with disabilities.

The Coalition's recommendation for fiscal year 2000 supports the President's $100 million increase for the Ryan White CARE Act titles and provides additional funding as well. The Ryan White CARE Act is the federal government's most significant HIV specific response to medical and support services. It is the federal portion of a partnership with communities who are challenged to find solutions to the difficult problems of health care access for people living with HIV. The CARE Act also provides for administration of the critical AIDS drug assistance programs which are providing new and promising therapies for HIV prevention. The AIDS Education and Training Centers provide essential training to health care providers nationwide in the evolving standard of care for people with AIDS.

Finally, the Coalition's recommendation for fiscal year 2000 supports the President's request for additional resources for Title X family planning services, which enable community-based clinics to provide basic reproductive health care to more than five million clients in over 4,000 clinics nationwide. Family planning services improve maternal and child health outcomes, lower the incidence of unintended pregnancy, and reduce the incidence of abortion. For every dollar spent on family planning services, more than $4 are saved in mandatory federal spending programs.

Substance Abuse and Mental Health Services Administration

[In billions of dollars]

Fiscal year 1999 appropriation	2.4
President's fiscal year 2000 request	2.6
CHF fiscal year 2000 recommendation	3.1

The Coalition recommends that $3.1 billion be provided to the SAMSHA in fiscal year 2000. This is $500 million (19 percent) more than the President has requested and $700 million (29 percent) more than provided in fiscal year 1999. The Coalition is especially pleased that the President has requested a $70 million increase for the Community Mental Health Block Grant and hopes Congress will provide this level of funding. Prior to fiscal year 1999 when Congress provided a $13.4 million increase, the Mental Health Block Grant had been level funded for seven years. This has resulted in erosion in funding to help communities address a serious and costly public health problem.

Agency for Health Care Policy and Research

[In millions of dollars]

Fiscal year 1999 appropriation	171
President's fiscal year 2000 request	206
CHF fiscal year 2000 recommendation	225

The Coalition is very pleased that the President has requested a 20 percent increase for the Agency for Health Care Policy and Research (AHCPR) which would provide the agency with $206 million in funding for fiscal year 2000. The Coalition's fiscal year 2000 recommendation provides $225 million, which is $19 million more than the President's request. This level of funding will enable AHCPR to evaluate the progress made in the implementation of various Congressional initiatives, such as the children's health insurance program. It will permit the agency to expand the number of evidence-based practice centers, expand the number of centers for education and research on therapeutics and fund more grants on improving health care quality and outcomes.

The Coalition appreciates the opportunity to provide the Subcommittee with its recommendations for fiscal year 2000 funding for health discretionary programs and looks forward to working with the Subcommittee in meeting the very difficult challenges ahead.

COALITION FOR HEALTH FUNDING—DISCRETIONARY HEALTH PROGRAMS

[B.A. in millions of dollars]

	Fiscal years—			Difference President CHF fiscal year 2000 recommendation	Difference fiscal year 2000 CHF 2000 recommendation
	1999 appropriation	2000 President's request	2000 CHF recommendation		
CDC	$2,900	$3,100	$3,900	+$800 (+25%)	+$1,000 (+34%)
NIH	15,652	15,972	18,000	+2,028 (+13%)	+2,300 (+15%)
HRSA	4,108	4,200	4,900	+700 (+16%)	+792 (+19%)
SAMSHA	2,488	2,626	3,112	+486 (+18%)	+624 (+25%)
AHCPR	171	206	225	+19 (+9%)	+54 (+31%)
FDA	1,123	1,315	1,315	.....	+192 (+17%)
IHS	2,242	2,412	2,621	+209 (+8%)	+379 (+16%)
OPHS	85	148	153	.....	.....
Total public health ..	28,769	29,979	34,226	+4,247 (+14%)	+5,457 (+19%)

PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

The Council of State and Territorial Epidemiologists (CSTE), an association of 450 state and local public health epidemiologists, appreciates this opportunity to provide the Subcommittee on Labor, Health and Human Services, and Education Appropriations with its recommendations for funding in fiscal year 2000.

The issue of epidemiologic capacity within state and local health agencies continues to be a principal concern for the organization. CSTE has had projects funded to specifically assess the epidemiologic capacity of broad program areas at the state level, such as chronic disease, and has concluded that the current method of categorical funding for infrastructure does not provide for the critical scientific services of epidemiologists. With this as an overarching concern—flexibility at the state level—CSTE offers seven specific funding recommendations for fiscal year 2000.

—First, CSTE strongly supports the President's fiscal year 2000 $65 million initiative to establish a national electronic public health surveillance system. Of this amount, $40 million is derived from funding the President has requested for bioterrorism within the Centers for Disease Control and Prevention (CDC) and $25 million is derived from new funding for infectious diseases, food safety, and Hepatitis C surveillance, also within CDC.

Establishing a national, integrated, public health surveillance system is a goal CSTE has sought for several years. Epidemiologists working in public health agencies are responsible for monitoring trends in health and devising prevention programs that enable the entire community to be healthy. Public health assessment includes surveillance, epidemiologic studies, program monitoring of diseases, risk fac-

tors for disease, health hazards, and preventive actions. Surveillance enables public health officials to:

—recognize outbreaks and intervene to prevent additional cases; this is critical in any bioterrorism attack;

—identify priority health problems/needs so that resources can be appropriately allocated;

—identify high risk communities and groups to effectively target programs;

—monitor the effectiveness of public health programs;

—identify issues that need further scientific study to devise preventive strategies.

While these core surveillance activities are critical to the success of public health efforts, they have historically had no stable source of funding. CDC does provide funding support for a few well-developed surveillance systems, but they are designed to meet the needs of that specific program and cannot be linked easily to other data systems to increase understanding about disease trends and health needs. In addition, the current fragmented, and underfunded network of surveillance systems often results in unnecessary duplication of effort. Much information from critical local reporters is frequently is provided via hand-written reports that must be re-entered into computer systems.

CSTE has been working within CDC, for several years, to develop an over-arching model for integrated public health surveillance that encompasses development of standards and criteria from which all programmatic surveillance systems, at the federal, state, and local levels, would be built. The President's national electronic surveillance initiative would provide critical and timely support to significantly enhance this effort. It would also provide funding to electronically link key health data reporting sources, such as local clinical laboratories and emergency rooms.

The establishment of a national electronic public health surveillance system would greatly enhance our nation's ability to quickly detect a bioterrorist attack, particularly one that is unannounced and involves a biologic agent with an incubation period of days or even weeks before clinical symptoms are evident. Speed in detecting an attack and identifying the terrorist agent in turn speeds response to victims and prevents death, spread of the disease, and economic disruption. A national electronic surveillance system would also be used—every day—to improve our ability to respond to public health problems such as food bourne illness, naturally occurring emerging infectious diseases, chronic diseases, occupational diseases and injuries, and environmental health hazards.

—Second, CSTE recommends that support provided within the fiscal year 1999 bioterrorism initiative for public health infrastructure continue in fiscal year 2000 and be increased from $121.7 million to $263.5 million. Within this total amount, CSTE also recommends $15 million to increase state and local epidemiologic capacity.

This amount reflects CDC's professional judgement about what is really needed to enhance eroded public health infrastructure to prepare the nation. Much of the responsibility for addressing the health consequences of a terrorist attack involving biological or chemical agents resides with the state and local public health community. This includes detecting the threat; identifying the agent involved through laboratory analysis; assessing the extent of exposure, location of the agent source and evaluation of its continuing danger to the public; coordinating treatment and prevention measures with the medical care community including transport of victims to appropriate treatment settings, distribution of stockpiled vaccines, antibiotics and other treatment measures, and quarantine in the case of an infectious agent.

It is very important that every state be prepared to address a bioterrorist attack, particularly because if it involves an unannounced attack using a biologic agent such as Anthrax or smallpox, two of the most likely agents, it will be days before the first cases begin appearing in physician offices, emergency rooms, and health clinics. By then, given our highly mobile society, victims are likely to be spread across many states.

Currently, virtually no state is prepared for a serious bioterrorism attack. Most states do not have even one professional epidemiologist to conduct full-time active surveillance for unusual diseases and occurrences—a fundamental requisite for bioterrorism preparedness, and for every day public health crises. Only one-third of states have a Biosafety Level 3 laboratory, critical for safely identifying terrorist agents. Fully 40 percent of local health departments are not "on-line" and cannot communicate electronically with their own state health departments.

The fiscal year 1999 bioterrorism funding provided to CDC, while extremely helpful in initiating preparedness, is only enough to support needed core epidemiologic and laboratory capacity in about half of the states. CDC has estimated that over $250 million is needed in fiscal year 2000 to adequately fund state and local public

health infrastructure needs. CSTE, and many other core public health organizations believe the level must be at least $263.5 million (see attached table).

This amount reflects CSTE's assessment that funding within the bioterrorism initiative for enhancing state and local epidemiologic capacity should be increased from $7 million to $15 million. At an average cost of $200,000 for each appropriated staffed epidemiolgical unit—including a full-time professional epidemiologist, computer, and statistical as well as support staff—$7 million will only support 35 of these units to conduct active surveillance for unusual diseases and occurrences and determine and implement an appropriate response to minimize adverse outcomes. Active surveillance means educating key reporters, such as emergency physicians and nurses, about the clinical symptoms associated with terrorist agents and the need to provide appropriate samples for laboratory analysis. It also means monitoring, at least weekly, essential reporting sources such as clinical laboratories, large provider group practices, emergency rooms and vital statistics bureaus for unusual deaths.

As already noted, only a handful of the largest, most resource rich states are able to support epidemiologic units that conduct the kind of active, generic surveillance and investigation needed to quickly detect an unannounced bioterrorism event involving a biologic agent. Even fewer of the identified 120 high risk cities have professional epidemiologists available that are not committed to other specific program needs. This means that $7 million to fund 35 appropriately staffed epidemiologic units cannot provide the kind of epidemiologic capacity required at both the state and local level for the nation to be prepared for a serious bioterrorism incident. CSTE recommends doubling the funding to $15 million in fiscal year 2000 which would provide for a minimum of 70 epidemiologic units. This would be enough to cover every state and a significant portion of the 120 highest risk cities.

CSTE also strongly supports, within the attached public health infrastructure budget, the $52 million allotted in fiscal year 2000 for stockpiling vaccines and antibiotics for civilian use. CSTE also supports $30 million for NIH for vaccine and treatment research and $13 million for FDA for rapid vaccine approval. Without treatment and prevention tools, public health and medical care professionals will have much less to offer victims of a bioterrorist attack.

It is important to note, again, that increasing state epidemiologic capacity to be prepared for a bioterrorism threat means each state will also be better prepared for detecting and responding to naturally occurring infectious diseases, food bourne illness, environmental health hazards, chronic disease, occupational disease and injury.

—Third, funding for the Behavioral Risk Factor Surveillance System (BRFSS), a proven and valuable tool, should be increased by at least 10 percent in fiscal year 2000.

The Behavioral Risk Factor Surveillance System (BRFSS) is the only source of state level behavioral data. These data are the basis for many intervention programs, policy decisions and budget direction for chronic and other diseases for several state health departments. The BRFSS is currently in its 15th year of operation and is the largest continuous telephone survey in the world. It is flexible, timely and allows for state-to-state and state-to-nation comparisons of data. The BRFSS is able to address emerging health issues and fewer resources are required to run BRFSS than is required to run in-person interviews. The state-based telephone surveys are used to monitor health behaviors and knowledge regarding, for example, tobacco use, physical inactivity, poor diet, alcohol use, and lack of preventive services (i.e., screening and immunizations).

In spite of all the data that BRFSS provides and the role these data play in the development of intervention programs and policy decisions, CDC funding for BRFSS is discretionary and averages $62,000 per state. Although states support a majority of the costs of BRFSS data collection, few are able to analyze and translate the data into long-term disease prevention and control programs and policies due to a lack of resources. For these reasons, CSTE urges that for fiscal year 2000 CDC provide a ten percent increase in funding for the BRFSS.

—Fourth, CSTE recommends that $20 million be provided to CDC in fiscal year 2000 to assist state and local health departments develop asthma prevention and control programs.

Asthma affects more than 14 million Americans, including five million children. The burden of asthma falls disproportionately on African-Americans and Hispanic populations and appears to be particularly severe in urban inner cities. In addition to the increasing proportion of the population with asthma, asthma morbidity and mortality are also increasing. Over 5,000 people died from asthma in 1995, and asthma accounts for nearly 500,000 hospitalizations each year. The health care costs

associated with asthma exceeded $6 billion in 1990 and experts predict that those costs could climb to more than $14 billion by the year 2000.

In spite of significant advances in the diagnosis and treatment of asthma, an improved understanding of the environmental triggers of asthma attacks, the health burden of asthma in the United States is increasing at epidemic proportions. Asthma control and prevention requires a long term, multi-faceted approach that includes patient education, surveillance, and control programs. These programs are not available due to a lack of resources at the state level. CSTE recommends that funds should be made available to CDC to develop asthma prevention and control programs at the state and local level.

CDC's national strategy to assist States in developing prevention programs is to focus on:

—promoting healthy home environments
—translating science into public health practice
—providing patient and community-level education and developing prevention partnerships
—defining the problem, the cause, effective prevention measures and ways to accomplish prevention goals.
—Fifth, CSTE recommends $45 million in fiscal year 2000 for CDC to support needed epidemiologic capacity for states as they move from AIDS case surveillance to HIV surveillance. CDC will soon publish state guidelines for HIV case surveillance, but has requested no additional funds in fiscal year 2000 despite a 100 percent increase in the time and effort required by state epidemiologists.

Currently, 31 states conduct HIV case surveillance. In anticipation of guidelines for conducting HIV case surveillance which will soon be published by CDC, most of the remaining states are moving to implement HIV reporting within the next year.

CDC estimates that there are 200,000–250,000 people living with HIV (not AIDS) in non-HIV reporting states. These cases will be eligible to be reported to state and local health departments during the next one-to-two years as HIV reporting is phased in by these states. During the same time period, all states will continue to report AIDS cases and deaths as well as newly diagnosed HIV infections. To accommodate the reporting of a very large volume of case reports during the next few years, in addition to the routine case reporting volume managed by state and local surveillance staff, additional resources are needed by the Surveillance and Statistics and Data Management Branches at CDC, and by state and local areas.

Supplemental funds are needed to support three major activities that will enhance the current epidemiologic capacity for HIV surveillance at the state level. These are:

(1) Implementation of HIV case surveillance for most states that do not currently conduct this kind of surveillance. This includes case finding and follow-up activities, which will require additional support to: establish laboratory-initiated reporting of over 200,000 current HIV cases using the existing HIV/AIDS Reporting System (HARS) Infrastructure; and develop statistical procedures and adjustments to improve the states' abilities to analyze and interpret HIV data.

(2) Evaluate how well HIV/AIDS surveillance data meet established criteria for the performance of surveillance systems, including completeness, timeliness, and representativeness of the surveillance data.

(3) Provide technical assistance on the development of new surveillance methods to areas that plan to implement HIV case reporting using coded (non-name) identifiers.

(4) In addition, under the new CDC guidelines, states that are already conducing HIV surveillance will need to add reporting of viral load tests for individuals identified as HIV positive as well as continue to conduct and report antibody testing to identify those who are HIV positive. This will add considerably to the workload of state health departments that are already conducting HIV reporting.

—Sixth, CSTE supports restoring the $30 million cut to the Preventive Health and Health Services Block Grant in the President's fiscal year 2000 budget and increasing the program above the fiscal year 1999 level of $150 million. States have estimated that $182 million is needed to assist them in meeting identified Healthy People 2000 goals.

The Preventive Health and Health Services Block Grant (PHHS) is the only source of flexible public health funding for many states to address the Healthy People 2000 goals they have identified as important for their population. Categorical funding does not always meet the needs of individual states and can hamper efforts to address actual existing health problems. The PHHS Block Grant fills in the gaps left by categorical programs.

States are accountable to CDC on how they spend block grant funding. Examples of how states use funding are:

—to prevent cardiovascular diseases through "heart healthy" community programs;
—to control communicable diseases through funding core state and local staff positions;
—to prevent injuries through the encouragement of bicycle helmet use;
—to provide funding for state or community emergency medical services.
—Seventh, CSTE supports $705 million in fiscal year 2000 for the Maternal and Child Health Block Grant administered by the Health Resources and Services Administration (HRSA).

The Maternal and Child Health Block Grant (MCH) provides a safety net of medical care services for women and children with special needs who cannot afford private health insurance and are not eligible for Medicaid. State MCH program plan and implement the following community based activities:
—prenatal care (every dollar invested yields three dollars saved);
—targeted efforts to prevent low birth weight babies, a costly condition which often results in lifetime disability;
—childhood immunizations;
—newborn screening;
—early intervention for children with chronic diseases and disabilities.

In 1996, the MCH program provided care to over 17 million infants, children and adolescents; 1.7 million pregnant women; and approximately 900,000 children with special health care needs. Over the past decade, we have seen an increasing demand for the services of MCH programs due to increasing numbers of uninsured and underinsured women and children. MCH programs are also experiencing increased demand due to the enactment of the Children's Health Insurance Program (CHIP) as they are an important link in the effort to locate, assess and refer eligible children for expanded Medicaid coverage under the program.

CSTE appreciates the opportunity to provide the Subcommittee with its funding recommendations for fiscal year 2000. The seven priority areas described are not single year concerns, but reflect on-going recognition of public health infrastructure deficits, areas of great potential scientific opportunity and recognition of changing health care needs.

Prepared Statement of Tom Van Coverden, CEO, National Association of Community Health Centers

On behalf of the National Association of Community Health Centers, I am pleased to provide the Subcommittee with testimony in support of the urgent need to increase funding by $100 million for the Consolidated Health Centers Program (i.e., community, migrant, homeless, and public housing health centers) to $1.026 billion for fiscal year 2000. Health centers can provide an entire year of primary and preventive care to an uninsured patient for an average of just $280 in federal support. The $100 million we seek for next year will allow health centers to care for an additional 350,000 uninsured patients. Since health centers have seen an additional 1 million uninsured patients over the past three years (about 350,000 each year), the increase would provide the minimum needed to match the flow of new uninsured patients seeking care.

I would like to express our deepest appreciation to the Subcommittee for its support of the consolidated health centers program. Under the leadership of Chairman Specter, appropriations for the program increased by $100 million last year—during a time when the Subcommittee had to face many difficult choices among worthwhile programs. Over 500 health centers received their first base funding increase in eight years. The $100 million increase this committee provided for health centers last year is an important step in bolstering the ability of Lake County and other existing health centers to extend care to the many new uninsured families now seeking services, and to develop new health center sites in needy communities that are currently unserved.

However, much more work needs to be done. During testimony to the House Labor, HHS, and Education Appropriations Subcommittee earlier this year, the Health Resources and Services Administrator, Dr. Claude Earl Fox stated that, in his professional judgment, health centers need a $264 million increase in fiscal year 2000 to maintain operations and meet the growing demands for services. The appropriations increase for fiscal year 1999 allows the Bureau of Primary Health Care to provide only 25 percent of the amount needed to adequately fund existing health centers which are currently underfunded for the number of uninsured they are serving. And, it will only permit funding for 50 of the more than 550 requests for a new health center submitted by communities that do not have one. Dr. Marilyn Gaston,

Director of the Bureau of Primary Care, testified before the same Subcommittee that 45 percent of health centers have been identified as financially at risk: between 5 and 7 percent are close to bankruptcy, and another 5 to 10 percent are in severe financial trouble. Already between 60 and 70 health center delivery sites have closed their doors, leaving patients without health services.

Two converging forces in the health system are pressing health centers across the nation hard. First is the growing number of uninsured and underinsured Americans. Forty-three million Americans lack any health coverage whatsoever and the vast majority cannot afford to pay for needed care themselves. The number of uninsured Americans is growing rapidly, at a rate of more than 100,000 per month. Studies have shown that this number could reach 50 million or more over the next five years. Nearly three-fifths of the uninsured are members of low-income working families who cannot afford to buy health insurance. Many of these uninsured individuals must rely on health centers, because we are among the precious few health care providers who are obligated to make our services affordable for those families by discounting our charges according to income.

Second, health centers are seeing increasing numbers of uninsured patients previously seen by other providers. The rapidly expanding use of managed care has triggered substantial cut-backs in the amount of free and reduced price care that is provided by private physicians and teaching hospitals. A recent study published in the Journal of the American Medical Association quantified managed care's dramatic impact on private physicians' care for the uninsured. It found that:

—Physicians who derive most of their practice revenue from managed care provide 40 percent less free or reduced price care. Greater financial pressures by third-party payers limit their ability to cross-subsidize care for the medically indigent.

—In markets with high managed care penetration, physicians provide less free or reduced price care regardless of their own level of involvement in managed care.

As cost pressures result in less free or reduced price care by private physicians, the burden of providing such care shifts onto health centers. Continuing increases in the number of uninsured persons we serve are severely straining our limited resources. While we are grateful to the Subcommittee for its continuing support, funding for the health centers program has not kept pace with the growing number of uninsured seeking care at health centers. If these trends were not challenging enough in their own right, the health center safety net is also endangered by a provision in the Balanced Budget Act which takes effect on October 1. This provision phases out the requirement that health centers be reimbursed on a reasonable cost basis for providing health care services to Medicaid beneficiaries. Enacted by Congress in 1990, the reasonable cost payment system brought an end to a period when underpayments from Medicaid forced us to siphon funds away from Federal Public Health Service grants we receive to support care for the uninsured. If the phase out of this payment system is not reversed or changed, it is estimated that health centers could lose approximately $50 million in Medicaid revenues in fiscal year 2000 alone. Every dollar of lost Medicaid revenue must be subsidized by these grant funds. As a result, this one-year $50 million loss will cost 178,500 uninsured people access to health center services. These financial losses will escalate to approximately $100 million (resulting in the loss of care for 357,000 uninsured) in fiscal year 2001, $150 million (536,000 uninsured) in fiscal year 2002, $300 million (1.1 million uninsured) in fiscal year 2003, and as much as $500 million (1.79 million uninsured) in fiscal year 2004.

As not-for-profit health care providers, all revenues that health centers collect are reinvested back into the health center to expand service sites, health care services, or hours of operation for the communities they serve. Likewise, all revenues that are lost by health centers force them to close delivery sites, limit needed health care services, or restrict the hours that health centers are available to the patients that require their services. This phase-out will devastate the good work this subcommittee has done to support health centers, especially over the last three years. The strain on the health center safety net will affect millions. Without health centers, residents of inner-city and rural underserved areas would face great unmet health care needs. Health center patients include uninsured low-income persons, minorities, rural residents, high-risk pregnant women and children, migrant and seasonal farm workers, persons with AIDS, persons with drug and alcohol problems, homeless persons and families, the frail elderly and other high-risk groups. Health centers have special expertise in meeting the unique needs of these most vulnerable populations and are often the only local source of non-hospital, community-based primary care for them. Their patients include:

—Children: Health centers serve 1 of every 6 low-income children (4.5 million children), including 1 in every 5 low-income uninsured children (1.3 million).

—Pregnant Women: In 1997, the 400,000 births to health center patients accounted for 1 of every 10 births (and 1 of every 5 low-income births) in the United States.
—Low-Income: Health centers care for 1 of every 8 low-income Americans.
—Uninsured: 1 in every 10 uninsured persons in the United States uses a health center (4.2 million).
—Minorities: Almost 7 million minority persons are health center patients.
—Rural Residents: Health centers are the family doctor for 1 in 12 rural Americans.
—Farmworkers: Health centers provide services to over one-half million farmworkers.
—Homeless: Over 430,000 homeless individuals receive care from health centers.

Nationwide, there are 981 community, migrant, homeless and public housing centers and FQHC look-alikes serving over 2,500 communities across America. Together, these health centers care for over 10 million children and adults in each state, Commonwealth and Territory, and the District of Columbia. Health centers are local non-profit, community-owned health care programs serving low-income and medically underserved urban and rural communities with few or no resources. Each local health center is governed by volunteer members of the community who have an interest and take responsibility to ensure that responsive and affordable health care is provided to all who need it. Patients are charged on a sliding fee scale to ensure that income or lack of insurance is not a barrier to care. Federal grants subsidize the cost of care provided to the uninsured and the cost of key services (such as translation and outreach) not covered by Medicare, Medicaid, or private insurance—services which make the care provided by health centers cost-effective and responsive.

Many studies have concluded that health centers, in the process of providing primary care to medically uninsured and underserved communities, achieve real and significant cost savings. Through fewer hospital admissions and less frequent use of costly emergency care for routine services, health centers save the American health care system billions annually. Few government programs have made as significant a contribution to low-income families as cost-effectively, or in high quality a manner as health centers.

Investing in health centers makes sense:

—Increases Access to Health Care: Every $100 million invested in health centers brings another $200 million in other resources to communities nationwide. This creates capacity for health services for 1 million people (including 350,000 uninsured persons), enabling them to get the care they need.
—Proven Track Record: Health centers are located in the communities where many uninsured people and those with poor health status live and work. They have a 30-year track record of controlling costs, providing access to quality care, retaining health professionals where they are most needed, and empowering communities to develop long-range solutions to their health needs.
—Cost-Effective, Quality Care: Health centers provide primary and preventive care for less than 76 cents a day for each person served (about $280 annually). They are required by law to meet strict quality, financial, and administrative standards.
—Saves Health Care Dollars: Health centers save community resources. Every grant dollar invested in health centers saves $7 for Medicare, Medicaid, and private insurance: $6 through lower use of specialty and inpatient care, and $1 from reduced use of costly hospital emergency rooms.

The National Association of Community Health Centers believes additional federal investment is needed to ensure the availability of primary and preventive health care in medically underserved communities. Priority should be given to stabilizing the existing health center safety net and expansion of existing health centers to serve the needs of communities without access to primary and preventive care. Health centers have been faced with the challenge of caring for an ever-increasing number of people seeking care in an era of stagnant or declining resources and shortages of primary care health professionals. As the number of uninsured persons increases, there must be a system in place that will provide essential health care services, especially for the most vulnerable, underserved people in our communities and in our nation. The health center system is already in place; it is cost-effective, efficient, accountable, and it works. We urge you to maintain and build on it.

As you consider the fiscal year 2000 appropriations, we request that you consider for the Consolidated Health Center Program (i.e., community, migrant, homeless and public housing): $1.026 billion, a $100 million increase above current funding levels. We know that you and members of the Subcommittee have a very difficult task ahead of you this year because of the strict limits on available funds. We have

characterized our recommended funding levels as an investment in a proven system of care to foster wellness and prevention. If funded adequately, the continued presence of health centers and the availability of basic health services will contribute to a healthier, more productive America.

Health centers were founded with a vision of community and consumer empowerment, and their experience over that past 30 years provides an object lesson on how consumer involvement can succeed where other models fail. Invest in health centers, build upon what has worked, look at the long history and success of the program and continue to invest in programs that mobilize communities to solve problems at the local level.

PREPARED STATEMENT OF THE PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE

Mr. Chairman, I appreciate the opportunity to place this brief statement in the record in support of the request made by the Philadelphia College of Osteopathic Medicine (PCOM). As you may know, PCOM is the largest osteopathic medical school in the country with a tradition that emphasizes medical training in primary health care and family practice.

Throughout its 100-year history, PCOM has sought to encourage its graduates to practice in low-income urban and rural communities. In fact, a considerable base of training for medical students is built around practical training regimens in urban clinics which PCOM operates in the Philadelphia area, and in affiliate training hospitals throughout Pennsylvania. In turn this approach, with its early clinical exposure, gives a balance in medical education between the classroom, the clinic and the community.

As the Committee is aware, the healthcare delivery system of the past was heavily weighted toward large urban medical centers with high technology bases. While this format certainly has its place, the focus has shifted to place the primary physician in the forefront, particularly in light of healthcare reforms and the emergence of managed care. In that context, the new training mandate is to train the generalist, and to focus more emphasis on areas of medical need—namely, preventative care and community medicine in low-income rural and urban areas.

Accompanying the shift in focus within the American healthcare system is a change noted in the 1995 Pew Health Professions Commission Study. This document indicated a massive oversupply of specialists and, thus, a need for more primary care physicians to balance the healthcare equation. Not only did the Pew Study recommend a 50/50 balance between specialized medicine and primary care, but it stressed early exposure to clinical practice settings for medical students, and overall care for the health of a community.

The Philadelphia College of Osteopathic Medicine believes that physicians must understand those they serve, and must create ways within a community to encourage those who have not sought healthcare in the past. To implement this philosophy, PCOM introduces students, early on, to a balance between the classroom, the community and the clinical experience, as I noted earlier. In short, PCOM's philosophy is in line with the Pew Study.

As the focus on primary care has become more pronounced, the number of osteopathic physicians has increased some 50-percent. In fact, osteopathic medicine has become one of the fastest growing health professions in the United States. This growth is, in large part, a reflection of the many benefits available to the patient base served by osteopathic physicians and the demand for primary care, in general.

In recognition of the increased demand for healthcare provided by osteopathic physicians, and as part of a continuing effort to improve physician training in the areas of preventative and family healthcare delivery, PCOM has commenced a dual enhancement initiative: one, PCOM has invested heavily in a renovation program for the four clinics it operates (3 urban and 1 rural); two, PCOM has underway, the establishment of an Urban-Rural Medical Exchange Network to interlink its clinics, the main campus and the fourteen affiliate training hospitals throughout Pennsylvania.

In the clinic renovation program, the four clinics will be (and are being) renovated to reflect the type of clinical environment which should be available to those who have been medically underserved over the years. Given the increasing demand for healthcare services in each of those clinics, it is necessary to expand and update each so that each can remain within accepted medical standards for healthcare delivery, and within the guidelines of the Federal government's focus on improved healthcare in underserved areas.

In the Urban-Rural Medical Exchange Network initiative, the focus is on outreach to the underserved communities in which the four PCOM clinics operate, online re-

sources to students training in the fourteen affiliate hospitals around Pennsylvania, and electronic imaging, diagnostic and lecture exchanges between practicing physicians and students. Apart from the medical education advantages of the Exchange Network, this initiative will enhance patient care by providing real-time patient data exchanges between clinics and affiliate hospitals—a plus for many underserved areas.

Significant funds have already been advanced toward both projects by PCOM. An ongoing capital campaign will raise yet more for this multi-phase program. However, at this stage, it is important that PCOM seek $3 million in Federal grant assistance for the entire initiative to continue forward at a smooth pace at this juncture.

Mr. Chairman, as you know, there are various precedents for this type of effort within the HRSA section of the bill. Accordingly, we ask that you give serious consideration to this request as it is a worthwhile one which stands to benefit thousands of urban and rural Pennsylvania residents who are among the population we call medically-underserved.

Thank you for your consideration.

PREPARED STATEMENT OF HON. PEDRO ROSSELLÓ, GOVERNOR OF PUERTO RICO

Both prior to and throughout the six years during which I have had the privilege of serving the nearly 3.9-million United States citizens of Puerto Rico as their Governor, health care has been one of my top priorities. Upon my inauguration in January 1993, Puerto Rico's health care system was plagued with chronic service problems and a bloated bureaucracy. Costs were skyrocketing, yet the quality of care remained woefully deficient. When uninsured economically-disadvantaged citizens required medical attention, they had only one alternative: to visit a government-operated clinic where long waits and substandard care were the rule, not the exception.

In keeping with a promise I had made as a candidate, my administration began immediately to design, enact and implement an innovative program of health-care reform; today, that program is close to reaching its goal of ensuring that every resident of Puerto Rico has access to quality health care through a system of private insurance, while simultaneously optimizing the utilization of our territory's health-care resources.

The ongoing reform of Puerto Rico's health-care system encompasses two parallel processes. First, through a competitive bidding process, public health-care facilities (such as clinics and hospitals) are being privatized in order to bring about service-delivery improvements. Second, again through competitive bidding, private firms are being contracted to insure the medically-indigent population.

With respect to the latter initiative, our government is purchasing insurance from private carriers to provide coverage for those who cannot afford to purchase it themselves. The insurance company bears the associated risks. Fees are determined by an individual's ability to pay. Thus, under this new system, the government is being converted into a facilitator—rather than a direct provider—of health-care services.

Now protected by private health insurance are more than 1.5-million Puerto Rico residents who formerly were categorized as medically indigent. The quality of care has dramatically improved; and the range of services being offered by clinics to attract patients (for example: extended operating hours, prenatal care, drug treatment programs and dental attention) continues to expand.

Puerto Rico has entered the vanguard of the U.S. health-care-reform movement because we put into practice a basic principle that is the goal of every health advocate: Health care should be the right of all, not the privilege of a few.

We are focusing close attention on ensuring that the highest possible percentage of each health-care dollar is specifically invested in serving the patient population: Administrative matters now consume less than 8 percent of Puerto Rico's health-care budget. Meanwhile:

—the number of new cases of Acquired Immune-Deficiency Syndrome [AIDS] has plummeted by 70 percent since 1993;

—a massive infant-vaccination program has been so successful that we have repeatedly been ranked first in the entire United States, with participation rates as high as 88 percent (compared with 38 percent in 1992);

—from a level of 13.4 deaths per 1,000 live births in 1993, the infant-mortality rate has been brought down to 9.3; and

—the life-expectancy rate has been steadily rising, to its current level of more than 74 years.

Independent surveys have determined that the beneficiaries of our health reform embrace it enthusiastically: Majorities that range from 90 percent to as high as 96

percent of the participants consistently affirm that they never want to go back to the old system. They enjoy their empowerment. They love getting the bureaucracy off their backs.

Six years ago, private health insurance and the federal Medicare insurance program combined to protect 55 percent of the Puerto Rican people; today, fully 95 percent of our people enjoy such protection; and before the end of next year, Puerto Rico will have established health care as a fundamental right in our society. Almost nowhere else has this been done, but it is being done in Puerto Rico.

Still, that comprehensive health-care reform initiative cannot possibly achieve its full potential until Congress has eliminated the existing inequities we confront with respect to such national programs as Medicaid, Medicare and Children's Health Insurance. This statement addresses one of those national ventures: the Children's Health Insurance Program [CHIP]. Created by the Balanced Budget Act of 1997, CHIP empowers the states to initiate and expand health-insurance coverage for minors. Under CHIP, the aggregate funding for U.S. territories was originally fixed at just 0.25 percent of the total program funding, and Puerto Rico's allotment was set at $9.8-million. So minimal was this federal appropriation that it was insufficient to underwrite even as much as $32 in health-care-insurance coverage annually for each eligible child in Puerto Rico. By contrast, eligible children residing in the 50 states receive an average of $588 apiece in annual coverage under CHIP.

In an effort to compensate for this disparity, Congress included an additional CHIP allotment of $32-million for the territories in the Omnibus Consolidated and Emergency Supplemental Appropriations Act of 1999 [PL 105–277]. However, this additional funding was assigned for fiscal year 1999 only; consequently, in fiscal year 2000 and every year thereafter, funding for Puerto Rico would revert to its previous statutory limit of $9.8-million.

Pursuant to President Clinton's pledge that more-equitable funding would be provided for children's health care in U.S. territories, the Administration's fiscal year 2000 Budget Request contains a CHIP funding increase of $144-million for Puerto Rico and the other territories; those funds are earmarked for distribution over a five-year period. Although this enhanced allocation would fall short of granting health-care-insurance parity to Puerto Rico's needy children, it unquestionably constitutes a positive step in that direction.

Accordingly, I respectfully urge the members of this Subcommittee to demonstrate the commitment of Congress to the cause of equal social justice for hundreds of thousands of our Nation's youngest citizens in the critical field of health-care by supporting that proposal and approving at least the sum of $34.2-million that is required for fiscal year 2000.

This additional funding is essential if Puerto Rico and the other territories are to protect their eligible children via adequate health-care insurance coverage. In the final analysis, after all, America's future depends upon healthy citizens; and a child denied health-care equality in a territory today may tomorrow become a public-health burden as an adult patient residing in one of the states. Thus, from even the narrowest of perspectives, it would be shortsighted—as well as unfair—to leave youngsters in the territories inadequately covered under CHIP.

I thank you sincerely for your consideration of this Statement.

PREPARED STATEMENT OF ROBERT FISH, PRESIDENT, SANTA ROSA MEMORIAL HOSPITAL, SANTA ROSA, CA

Mr. Chairman, and Members of the Subcommittee, thank you for the opportunity to submit testimony to the hearing record regarding the proposed Northern California Telemedicine Network. This network will consist of a hub located at Santa Rosa Memorial Hospital in Santa Rosa, California and will serve over 10 hospitals, health centers and clinics in Sonoma, Napa, Mendocino, and Humbolt counties.

Santa Rosa Memorial Hospital is moving aggressively to build a permanent telemedicine infrastructure to expand health care services, as well as education and prevention programs into these currently underserved areas. The core of this initiative will be located at the Santa Rosa Memorial Hospital Emergency Department that will serve as the "hub," for this regional telemedicine network, providing access to primary, specialty and trauma care services.

The Northern California Telemedicine Network will work with other institutions to develop twelve "spoke" sites throughout northern California during the initial years of the project including:

—St. Joseph's Hospital, Eureka, California
—Redwood Memorial Hospital, Fortuna, California
—Mendocino Coast District Hospital

—Petaluma Valley Hospital
—Rohnert Park Healthcare Center
—Redwood Coast Medical Services
—Anderson Valley Health Clinic
—Mendocino Coast Clinics
—Potter valley Community Health Center
—Long Valley Health and Dental Center
—Mendocino Community Health Clinic

The growth of this network will enable a telemedicine program to achieve maximum cost effectiveness by serving multiple spoke sites from a single hub. In addition, it is anticipated that the spoke sites will develop some synergies as a result of their telemedicine technology that will allow them to communicate more effectively with each other and, importantly, with the communities most urgently in need of those services through the use of telemedicine technologies.

As I am sure that you are aware, rural America is experiencing a shortage of primary care physicians and specialist care providers. Primary care physicians are the keys to meeting the basic health care needs of patients in these areas because they are able to provide a wide variety of basic health services and identify medical problems needing further attention. Twenty-nine percent of rural residents live in Health Professional Shortage Areas (HPSA) compared to only nine percent of urban residents. Statistics from the Office of Statewide Health Planning and Development in California show that in northern California alone, all of Del Norte county and portions of Sonoma, Mendocino, Lake and Humboldt Counties are all experiencing Primary Care Health Professional Shortages.

People living in remote areas struggle to access timely, quality medical care. Residents of these areas often have substandard access to specialty health care, primarily because specialist physicians are more likely to be located in areas of concentrated population. Because of innovations in computing and telecommunications technology, many elements of medical practice can be accomplished when the patient and health care provider are geographically separated. This separation could be as small as across town, across a state, or even across the world.

Many areas in California, specifically Northern California are medically underserved areas. The United States Department of Health and Human Services has classified portions of Sonoma, Mendocino, Humboldt, Del Norte counties and all of Lake county as federally designated medically underserved areas. Access to medical care, especially specialty and trauma care is limited and episodic at best.

Often, these communities have been medically underserved due to the concentration of specialty care and health education in urban and suburban neighborhoods. The use of Telemedicine serves to provide California's underserved patients with the medical services they need. Instead of the patient being forced to travel long distances to reach a specialized provider, the patient, instead, could see their local provider and receive specialized care via telemedicine saving time, improving safety and providing a much needed service for the patient. Additionally, the need for emergency transport of patients would be significantly decreased due to the ability of telemedicine to assist in the diagnosis of a trauma patient on site. California could significantly benefit from the development of telemedicine due to its large geographical area with a population located in big cities, smaller towns and isolated rural regions.

Telemedicine has the potential to improve the delivery of health care in America by bringing a wider range of services to underserved communities and individuals in both urban and rural areas. In addition, telemedicine can help attract and retain health professionals in rural areas by providing ongoing training and collaboration with other health professionals.

As you know, the Health Resources and Service Administration, a branch of the U.S. Department of Health and Human Services, recently created the Office for the Advancement of Telehealth with the mission of assisting to set up federal telemedicine policy, funding telemedicine demonstrations, providing technical assistance to grantees and local and state health officials and producing educational tools to promote the use of telemedicine. We feel that Santa Rosa Memorial Hospital's Northern California Telemedicine Proposal would be a worthy demonstration project to be funded through this newly created resource.

Mr. Chairman, we believe that Santa Rosa Memorial Hospital proposed Northern California Telemedicine Network will create a national model for providing access to primary, specialty and trauma care services for remote and at-risk populations. Our desire is to provide a much needed service—primary and specialty care—to these underserved communities. Therefore, Santa Rosa Memorial Hospital is federal support in fiscal year 2000 for the implementation of its Northern California Telemedicine Network. The federal investment will enhance our nation's commitment to

protecting the health of our citizens. Your support for this effort will improve the quality of health care and contribute to the saving of lives for thousands of individuals in Northern California.

Thank you for your interest.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE AND THE ASSOCIATION OF TEACHERS OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) and the Association of Teachers of Preventive Medicine (ATPM) are pleased to submit jointly this statement concerning appropriations for federal activities in disease prevention and health promotion. ACPM is the national medical specialty society of physicians whose primary interest and expertise are in preventive medicine. ATPM is the professional organization of academic departments, faculty and others concerned with undergraduate and postgraduate medical education in preventive medicine. Together, these organizations are proud to offer the public a high degree of knowledge and skill in disease prevention and health promotion.

ACPM and ATPM urge the Subcommittee to maintain federal support for prevention and public health. In particular, we urge a minimal increase in the level of funding for preventive medicine residency training and for training other public health professionals included in Title VII of the Public Health Service Act. We also urge an increase for the activities of the Centers for Disease Control and Prevention, the Agency for Health Care Policy and Research, and an earmark for the invaluable work of the Office of Disease Prevention and Health Promotion in the Office of the HHS Secretary.

We are well aware of the fiscal constraints that this Subcommittee faces and we do not make these recommendations lightly. However, we are deeply concerned that weakening our nation's efforts in disease prevention and health promotion will become an unintended consequence of necessary reductions in discretionary appropriations. At a time when the private sector is struggling mightily to contain medical care costs, the nation can ill afford a diminution in public health efforts to prevent disease that only the government can conduct. Compared to the vast sums of public funds that are spent on curative medicine and research, the amounts that we recommend be targeted to prevention are small indeed.

TRAINING IN PREVENTIVE MEDICINE AND PUBLIC HEALTH—$50 MILLION

Prevention, in its broadest sense, is practiced by all physicians and other health professionals who help their patients stay healthy. It also is the principal goal of our nation's state and local health departments, who perform core functions in health protection and promotion that no single private institution or health provider can fulfill. The specialty of preventive medicine bridges the gap between the perspectives of clinical medicine and public health.

The tools of preventive medicine are the population-based health sciences, including epidemiology, biostatistics, environmental and occupational health, planning, management and evaluation of health services, and the social and behavioral aspects of health and disease. These are the classic tools of practice in public health agencies, but they have grown in importance in other health care settings where there is increasing recognition that improving the health of a patient population and reducing the costs of medical care also require application of the population-based health sciences.

Departments of preventive medicine, community medicine, or social medicine in medical schools, schools of public health, and preventive medicine residency programs (which are located in medical schools, schools of public health, and a few health departments), are the loci of expertise in the population-based health sciences. Federal support for preventive medicine training and public health training is essential to help meet the workforce needs not only of public health departments, but also of a rapidly evolving health care system that must be cost-effective and accountable.

The small sums appropriated for preventive medicine residency training under Section 768 (formerly Sections 763), Title VII of the Public Health Service Act, have been the exclusive federal support for programs training physicians in general preventive medicine and public health (other than the residency programs conducted by the Centers for Disease Control and Prevention and the military). Medicare Graduate Medical Education (GME) funds have been largely unavailable to these programs because they are based not in hospitals but in community outpatient and public health settings. And even with the GME changes made in the Balanced Budget Act (i.e. payment to non-hospital based sites), preventive medicine

residencies are still not able to receive reimbursement because preventive medicine programs derive little or no revenue from one-on-one patient care—as a result, this common source of funds for physician training is unavailable.

Currently, residency programs scramble to patch together funding packages for their residents. Funding from any source is available for only 60 percent of preventive medicine residency positions. The remainder of the openings go unfilled due to lack of funds, and potential applicants must be turned away.

A 1991 survey of all 1070 graduates of general preventive medicine/public health residency programs from 1979 to 1989 conducted by Battelle, an independent consultant under contract to the Centers for Disease Control and Prevention and the Health Resources and Services Administration provided a clear picture of the accomplishments of the training programs and the impact of these federal funds. A majority of the graduates have initiated or managed major programs in prevention and control of infectious disease, chronic disease, sexually transmitted diseases, or maternal and child health. In addition to creating and running community health programs such as these, 60 percent of the graduates engage in research in disease prevention and health promotion, and 70 percent also take care of individual patients.

This survey also documented that funds invested in training these physicians have a lasting impact. Ninety percent of preventive medicine graduates remain involved in public health or preventive medicine. Moreover, Title VII funds were shown to be directly related to the viability of preventive medicine residency programs. In programs that have received federal grants, the number of graduates has more than doubled since 1983. Conversely, the number of graduates of programs that no longer receive federal funds has decreased significantly.

The training of public health professionals is closely linked to preventive medicine. The nation's 28 schools of public health provide training for physician specialists in preventive medicine as well as for many other health professionals who comprise our public health workforce. In addition to the shortage of physicians trained in preventive medicine, there are shortages of epidemiologists, biostatisticians, environmental and occupational health specialists, public health nutritionists and public health nurses. We urge your support of all the public health training programs included within Section 105, otherwise known as the Public Health Workforce Cluster, including: Public Health Training Centers (Section 766, formerly known as Public Health Special Projects), Public Health Traineeships (Section 767), and Preventive Medicine Residencies/Dental Public Health (Section 768). An appropriation of $50 million for Sections 766, 767, and 768 will allow for the continuation of efforts to build the nation's cadre of prevention professionals in fiscal year 2000. Finally, ACPM and ATPM support the Health Professions and Nursing Education Coalition's (HPNEC) recommendation of $316 million for all of the health professions education programs funded under Titles VII and VIII of the Public Health Service Act.

CENTERS FOR DISEASE CONTROL AND PREVENTION—$3.9 BILLION

Physicians working in preventive medicine and public health rely heavily on the expertise and activities of the Centers for Disease Control and Prevention, the nation's premier agency for disease prevention and health promotion. Therefore, we support, alongside many other organizations and coalitions with a concern for prevention, including the Coalition for Health Funding and the CDC Coalition, a total CDC appropriation of $3.9 billion.

Through funding of state and local prevention programs, research, training and surveillance, CDC has a major impact on every important issue in prevention. Compared to the billions that are spent on acute health care, our national investment in prevention continues to lag. The increases in health care costs we have witnessed are not a reason to cut back on funds appropriated for prevention. They are a reason to make a large investment now. Given the resources, CDC can play a critical role in revitalizing programs and services of proven effectiveness in reducing death and disability in this country. Reducing CDC funds would be an act of extraordinary shortsightedness. Time and again we have seen, as in the cases of tuberculosis and measles, when public health efforts falter, the nation pays a high price later in the costs of preventable disease.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH—$225 MILLION

The Agency for Health Care Policy and Research (AHCPR) is responsible for conducting groundbreaking research concerning the cost-effectiveness of health care services and has served as the focal point for coordinating departmental activities in prevention as well as innovative public-private partnerships. AHCPR provides guidance and prototype materials to health practitioners and patients through the

Put Prevention Into Practice project. It has also been actively involved with assisting the U.S. Preventive Services Task Force in its revision of the U.S. Guide to Clinical Preventive Services, the established reference source for clinicians, purchasers of health care, and students, trainees and researchers needing evidence-based recommendations on preventive services. We urge your support of $225 million for these and other projects implemented by AHCPR.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION—$4.6 MILLION

The Office of Disease Prevention and Health Promotion (ODPHP) stands out among federal agencies for its ability to leverage small amounts of funding into large accomplishments in highly innovative ways. ODPHP manages Healthy People 2000, and this year launched the Healthy People 2010 initiative, the national prevention strategy used by health agencies across the nation to set measurable objectives for health improvement. Explicit support for ODPHP is vital in signaling a continued federal commitment at the Secretary's level to leadership in prevention. We urge the Subcommittee to earmark $4.6 million for this office, an amount equivalent to fiscal year 1995 funding, before the budget for this office was incorporated into the amounts appropriated for the Office of the Secretary.

PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

The National Rural Health Association (NRHA) thanks Chairman Specter and members of the Subcommittee for the opportunity to submit for the record the NRHA's fiscal year 2000 funding requests for programs important to our nation's rural health care delivery system. We believe we can offer you an insightful look at the unique health care needs of rural and frontier Americans.

The NRHA is a national nonprofit membership organization that provides leadership on rural health issues. Through discussion and exploration, the NRHA works to create a clear national understanding of rural health care, its needs, and effective ways to meet them. The association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through grassroots advocacy, communications, education and research. As you are well aware, rural areas are unique. They differ from urban communities in their geography, population mix and density, economics, lifestyle, values and social organization. Rural people and communities require programs that respond to their individual characteristics and needs.

Membership of the NRHA is a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health. Individual members come from all disciplines and include hospital and rural health clinic administrators, physicians, nurses, dentists, non-physician providers, health planners, researchers and educators, state offices of rural health and policy-makers. Organization and supporting members include hospitals, community and migrant health centers, state health departments and university programs.

First, we would like to express to the Subcommittee the critical need for increased funding for the National Health Service Corps (NHSC). The NRHA strongly supports a $40 million increase for the program. In fact, the Corps is our membership's number one funding priority for fiscal year 2000. Of concern to the NRHA is the fact that the NHSC has received level funding the past three fiscal cycles.

The NHSC plays an important role in maintaining the health care safety net by placing primary care providers in both rural and inner-city underserved communities. Currently, 2,400 NHSC clinicians, including physicians, dentists, nurse practitioners, physician assistants, certified nurse midwives and mental and behavioral health professionals, provide primary care serves to 4.6 million Americans living in rural and inner-city areas that would otherwise go unserved.

Many of our members are former NHSC clinicians and can personally attest to the value of the NHSC in increasing access to quality primary health care services to our nation's underserved rural populations. Dr. Tom Dean, an NRHA past-president and former NHSC clinician who served in rural Kentucky, has been building a practice in South Dakota for over 20 years and now has a professional staff of six—three of which are NHSC clinicians. In recent testimony before the House Labor, HHS and Education Appropriations Subcommittee, Dr. Dean stated, "I can share with you frankly and without exaggeration that if it were not for the support of the NHSC program, my community's primary care practice would not survive, consequently leaving numerous residents of rural South Dakota without access to vital primary health care services. As a direct result of the NHSC, families in my community enjoy the benefits of a stable health care practice."

However, it is important for the members of the Subcommittee to keep in mind that the 4.6 million rural and inner-city residents benefiting from the work of NHSC clinicians represents only 20 percent of our country's total underserved population. It is estimated that over 19,700 additional clinicians are needed to eliminate the 2,800 Health Professional Shortage Areas (HPSAs), 1,116 dental HPSAs and 629 mental health HPSAs currently designated across our nation. Despite the common belief that the United States has more physicians than it truly needs, it is quite obvious from these statistics and the personal experience of NRHA members that this is not the case. The reality is that there is a maldistribution of primary health care providers in our country. The number of American families without access to necessary primary health care will continue to grow, unless the NHSC program, and the financial incentives it provides, is able to continue to meet the needs of our underserved communities.

As a result of recurrent level funding, the NHSC is estimating that it will be able to fill only 60 percent of the approximately 1,400 requests for primary care clinicians from underserved communities expected in 1999. A $40 million increase would provide the program with enough resources to place an additional 427 clinicians in underserved areas. Funding for this program also supports the important work of the fifty state offices of rural health.

A program instrumental to the survival of our nation's most vulnerable small, rural hospitals is the Medicare Rural Hospital Flexibility program authorized as part of the Balanced Budget Act of 1997 (BBA). The BBA established a nationwide limited-service hospital program to improve access to essential health care services through the establishment of Critical Access Hospitals (CAHs) and rural health networks. States are provided grants to collaborate with community health care leaders in developing state rural health plans and designating CAHs. In addition to implementation grants made available to states, CAHs receive reasonable-cost reimbursement for the Medicare services they provide.

This new program creates an important alternative for small, rural hospitals. The CAH program provides regulatory relief and more equitable financing options to rural hospitals by assisting states in proactively responding to market changes, removing restrictive standards, and supporting network development and regional approaches to health care. The Federal Office of Rural Health Policy will soon be awarding first year grants to state offices of rural health to assist them in the development of state rural health plans and health care networks, designation and conversion of CAHs, and the improvement of rural emergency medical services.

The NRHA applauds the work of the Subcommittee last year for ensuring the inclusion of first year funding for this program in fiscal year 1999 appropriations legislation and urges the Subcommittee to continue its support by providing second year funding of $25 million. This money is necessary to ensure states, communities and CAHs receive the financial support necessary to fully and properly implement the program as Congress intended.

Third, the NRHA requests that the Subcommittee provide $50 million for the Rural Health Outreach, Network Development and Telemedicine Grant program. This program, which was reauthorized in 1996, provides important grant opportunities to rural communities. Since 1991, over 300 rural communities have benefited from innovations in health care service delivery. Rural Health Outreach grants have never been more important to rural communities given recent documentation regarding the impact the changes in Medicare and Medicaid reimbursement policy contained in the BBA are having on our nation's rural health care delivery system.

A recent report by the Rural Policy Research Institute (RUPRI) states, "Various provisions of the BBA each affect a component of the rural health delivery system and their combined impact could lead to a radical restructuring of the system." The report entitled, "Taking Medicare into the 21st Century: Realities of a Post BBA World and Implications for Rural Health Care," also states that "Given low enrollment into managed care and limited use of any Medicare-risk plans in rural areas for the foreseeable future, the impacts of changes in traditional Medicare are of vital concern for the welfare of rural beneficiaries."

The program offers grants to rural communities working to provide health care services through new and innovative strategies including telemedicine and trauma care services. Rural outreach grants also provide funding to communities to develop formal, integrated networks of providers that may offer a range of primary and acute care services. Network development grants are designed to develop organizational capacity in the rural health sector through formal collaborative partnerships involving shared resources and possible risk-sharing.

One outreach grant in Lock Haven, Pennsylvania, provides health promotion classes and health screening program throughout rural Clinton County. Health screening services, conducted in local fire halls include checking for hypertension,

diabetes, elevated cholesterol levels, skin cancer and other conditions. Clients are referred to appropriate sources of care as needed. The grant also supports health education classes on such topics as diet, exercise, nutrition and diabetes control.

Another example of successful use of an outreach grant is in Marshalltown, Iowa, where medical and dental services are being provided to underserved children, youth and families through a school-based outreach program. Using a mobile medical clinic, services are rotated among four elementary schools. Hundreds of elementary school children have received primary medical care and dental services through this project. The grant has also established an emergency prescription drug reimbursement program for low income students and their families.

The NRHA recommends Congress provide $15 million for the Rural Health Research Grant program. This grant program currently supports five rural health research centers that provide policy relevant research to Congress and the U.S. Department of Health and Human Services relating to rural hospitals, health professionals, delivery of mental health services, functioning of managed care systems, and more recently, the impact of the Balanced Budget Act on the rural health care delivery system.

This program also provides approximately $8 million in telemedicine grants to improve access to quality health care services for rural and frontier residents through telemedicine technologies. Grantees of this program are demonstrating how telemedicine can be an instrumental part of a rural health care network in efficiently and cost-effectively providing health care services to the people it serves.

Consisting of 38 regional sites, the Marshfield Clinic Network of Marshfield, Wisconsin, provides extensive telecommunications network administration and business functions such as e-mail and patient care conferencing. Grant money is allowing the clinic to expand and provide clinical telemedicine services to two underserved communities—Park Falls and Ladysmith. Services currently being provided via telemedicine technologies are emergency medicine, oncology, psychiatry, dermatology, radiology, occupational medicine, nurse triage services and compliance follow-ups. Funding has allowed the Marshfield Clinic to provide these two communities with on-line patient and professional information and resources as well as to evaluate the human factor and clinical outcomes of telemedicine.

Another telemedicine grant is supporting a collaborative effort in Texas that is using telecommunications technology to improve rural emergency care services through a continuing education network for emergency care personnel. This network links rural providers with each other as well as with more specialized care sites. Additionally, the consortium members, which include Stephen F. Austin State University, Piney Wood Area Health Education Center, the Council for the Advancement of Rural Education, the University of Texas Medical Branch, and the University of Texas, Houston Health Science Center, have developed a wide range of educational programming for rural emergency medical technicians.

Increased funding is also needed for the Consolidated Health Centers programs, which provide primary health care services to our nation's rural and urban underserved populations. In fact, in many rural communities the only health care entity providing primary and preventive health care services to residents is a community health center (CHC). Overall, CHCs provide services to ten million residents of underserved areas, with about 50 percent of the users being from rural areas. CHCs have been proven to significantly improve a community's health especially when it provides maternal and child health care services as well as child immunizations. Migrant health services, which are included in this program, provide migrant and seasonal farmworkers with access to primary health care services.

It is important to note that CHCs have added more than 1 million uninsured patients to their rolls in the last three years alone as declines in uncompensated care by other providers have occurred due to lost revenues by commercial managed care plans. Adequate funding for CHCs is crucial given that over 80 percent of patients seen by CHCs have their care paid by Medicaid, Medicare and federal grants to care for the uninsured. The NRHA urges the Subcommittee to provide $1.25 billion for the Consolidated Health Centers program for fiscal year 2000 to continue improving the health status of our country's underserved populations.

Lastly, the NRHA is opposed to the 20 percent decrease for Health Professions programs contained in the President's fiscal year 2000 budget. These programs are the main source of education and training for rural health care providers as virtually all GME payments go to urban-based teaching hospitals. The association urges the Subcommittee to continue adequate funding for these vital programs, which enhance the ability of rural health care providers to care for rural and frontier residents.

The NRHA wishes to thank Chairman Specter and members of the Subcommittee again for the opportunity to submit for the record the NRHA's fiscal year 2000 fund-

ing requests. It is important that we work together to guarantee a healthier life for rural and frontier Americans. However, due to the geographical, distance and financial restraints that many rural and frontier communities face, this progress depends upon the assistance and leadership of the federal government. The NRHA stands ready to work with the Subcommittee and the Congress to ensure access and quality of essential health care services continue to improve for our country's rural and frontier residents.

NATIONAL RURAL HEALTH ASSOCIATION

[Dollars in millions]

	Fiscal years—					
	1999 Final	2000 NRHA	2000 Clinton	2000 House bill	2000 Senate bill	2000 Final
Rural Health Outreach and Network Development Grant Program	38.9	50.0	[1] 31.4	.....	.....	.....
	.....	(+11.1)	.....	.....	.....	.....
Rural Health Research	11.7	15.0	[1] 6.1	.....	.....	.....
	.....	(+3.3)	.....	.....	.....	.....
Office for the Advancement of Telehealth	0.0	0.0	[1] 13.0	.....	.....	.....
Rural Hospital Flexibility Program	25.0	25.0	25.0	.....	.....	.....
	.....	(0.0)	(0.0)	.....	.....	.....
Consolidated Health Centers Program	925.0	1,025.0	945.0	.....	.....	.....
	.....	(+100.0)	(+20.0)	.....	.....	.....
National Health Service Corps	115.4	155.0	115.4	.....	.....	.....
	.....	(+39.6)	(0.0)	.....	.....	.....
State Offices of Rural Health Program	([2])	5.0	([2])	.....	.....	.....
Family Medicine Training Departments of Family Medicine/Residency (HP)	51.1	56.2	.....	.....	.....	.....
	.....	(+5.1)	.....	.....	.....	.....
Physician Assistants (HP)	6.8	7.5	.....	.....	.....	.....
	.....	(+0.7)	.....	.....	.....	.....
Rural Interdisciplinary Training Program (HP)	4.3	4.7	.....	.....	.....	.....
	.....	(+0.4)	.....	.....	.....	.....
Allied Health Program (HP)	5.0	5.5	.....	.....	.....	.....
	.....	(+0.5)	.....	.....	.....	.....
Area Health Education Centers (HP)	33.4	36.7	.....	.....	.....	.....
	.....	(+3.3)	.....	.....	.....	.....
Nurse Special Projects (HP)	11.0	12.1	.....	.....	.....	.....
	.....	(+1.1)	.....	.....	.....	.....
Nurse Traineeships (HP)	16.5	18.2	.....	.....	.....	.....
	.....	(+1.7)	.....	.....	.....	.....
Nurse Anesthetists (HP)	2.9	3.2	.....	.....	.....	.....
	.....	(+0.3)	.....	.....	.....	.....
Nurse Practitioners/Nurse Midwives (HP)	18.3	20.1	.....	.....	.....	.....
	.....	(+1.8)	.....	.....	.....	.....
Subtotal Health Professions	304.3	334.7	252.0	.....	.....	.....
	.....	(+30.4)	(−52.3)	.....	.....	.....
AHCPR	171.1	171.1	206.0	.....	.....	.....
	.....	(0.0)	(+34.9)	.....	.....	.....
HCFA, Office of Research, Demonstration and Evaluation	50.0	50.0	55.0	.....	.....	.....
	.....	(0.0)	(+5.0)	.....	.....	.....
National Institute for Occupational Safety and Health: Agricultural Health and Safety	23.1	23.1	[3] 23.1	.....	.....	.....
	.....	(0.0)	(0.0)	.....	.....	.....
Infant Mortality Initiative—Healthy Start	105.0	105.0	105.0	.....	.....	.....
	.....	(0.0)	(0.0)	.....	.....	.....
Preventive Health Block Grant	150.0	150.0	120.0	.....	.....	.....
	.....	(0.0)	(−30.0)	.....	.....	.....
AIDS—Ryan White Title III	94.3	100.0	130.0	.....	.....	.....
	.....	(+5.7)	(+35.7)	.....	.....	.....
Black Lung Clinic Program	5.0	5.0	5.0	.....	.....	.....

NATIONAL RURAL HEALTH ASSOCIATION—Continued

[Dollars in millions]

	Fiscal years—					
	1999 Final	2000 NRHA	2000 Clinton	2000 House bill	2000 Senate bill	2000 Final
	.....	(0.0)	(0.0)	.....	.....	.....

[1] Funding previously contained in the Rural Health Outreach and Rural Health Research programs supporting telehealth activities has been transferred to the new Office for the Advancement of Telehealth.

[2] Report language allows $3 million to be allocated annually from the NHSC budget for the SORH program. The President's FY 2000 budget contains language providing funds for the SORH program from the NHSC allocation, but does not specify a specific dollar amount.

[3] Total funding for the NIOSH increased by six percent in the President's FY 2000 budget.

NATIONAL HEALTH SERVICE CORPS FIELD STRENGTH BY PROVIDER TYPE, DISCIPLINE, AND URBAN/RURAL STATUS FOR FISCAL YEAR 1998—(AS OF 09/30/98)

State	State total	Non-obligated Federal	Obligated Federal	NHSC SCH	NHSC LRP	State LRP	COMM SCH	MD/DO	DD	NP	PA	NM	M&BH	Other	Urban	Rural
Alabama	45	1	.....	17	23	.....	4	25	8	10	2	.....	.....	.....	15	30
Alaska	11	.....	.....	6	5	.....	.....	4	.....	3	4	.....	.....	.....	2	9
Arizona	48	1	.....	21	14	12	.....	31	2	5	9	.....	.....	1 (NU)	12	36
Arkansas	15	.....	.....	3	12	.....	.....	10	3	.....	.....	.....	2	.....	3	12
California	164	1	.....	31	53	78	1	93	23	17	28	.....	2	1 (NU)	80	84
Colorado	56	.....	.....	7	49	.....	.....	31	3	8	11	2	.....	1 (DH)	18	38
Connecticut	32	.....	.....	5	20	7	.....	11	5	7	3	4	2	.....	31	1
Delaware	4	.....	.....	1	3	.....	.....	4	.....	.....	.....	.....	.....	.....	4	.....
D. of Columbia	17	3	1	3	10	.....	.....	9	2	5	1	.....	.....	.....	17	.....
Florida	63	8	1	12	42	.....	.....	30	10	10	7	3	2	1 (POD)	19	44
Georgia	90	1	1	24	49	10	5	46	9	7	24	2	1	1 (NU)	41	49
Hawaii	4	1	.....	1	2	.....	.....	3	.....	1	.....	.....	.....	.....	2	2
Idaho	22	.....	.....	8	14	.....	.....	15	1	1	5	.....	.....	.....	.....	22
Illinois	82	.....	.....	22	45	15	.....	50	5	12	10	4	1	.....	69	13
Indiana	33	.....	1	11	21	.....	.....	16	2	6	3	2	4	.....	15	18
Iowa	29	1	.....	7	16	5	.....	16	1	2	9	.....	1	.....	10	19
Kansas	29	.....	.....	8	21	.....	.....	11	2	3	9	.....	4	3	26	
Kentucky	33	.....	.....	12	18	.....	3	16	3	4	5	1	4	.....	2	31
Louisiana	38	1	.....	7	9	21	.....	23	9	3	2	.....	1	.....	19	19
Maine	39	.....	.....	15	15	9	.....	22	3	4	8	.....	2	1	38	
Maryland	31	2	.....	4	9	16	.....	26	2	2	1	.....	.....	.....	11	20
Massachusetts	66	1	.....	22	31	12	.....	36	9	18	.....	2	1	.....	65	1
Michigan	153	1	.....	23	62	67	.....	89	19	10	28	5	2	.....	51	102
Minnesota	34	.....	.....	4	24	6	.....	15	.....	5	4	2	8	.....	5	29
Mississippi	35	2	.....	4	29	.....	.....	13	12	10	.....	.....	.....	.....	7	28
Missouri	69	2	.....	14	48	5	.....	39	5	16	2	.....	7	.....	25	44
Montana	13	.....	.....	3	10	.....	.....	10	.....	2	1	.....	.....	.....	.....	13
Nebraska	26	.....	.....	2	24	.....	.....	12	2	2	4	.....	6	.....	3	23
Nevada	13	.....	.....	4	3	5	1	6	.....	1	6	.....	.....	.....	2	11
New Hampshire	9	.....	.....	2	3	4	.....	5	.....	3	1	.....	.....	.....	4	5
New Jersey	23	1	.....	2	11	9	.....	11	9	.....	1	1	1	.....	14	9
New Mexico	47	3	.....	10	19	15	.....	14	13	11	6	1	2	.....	8	39
New York	190	.....	.....	19	125	46	.....	112	29	13	25	8	3	.....	164	26
North Carolina	115	6	.....	31	58	20	.....	60	4	10	37	3	1	.....	14	101
North Dakota	6	.....	.....	2	4	.....	.....	3	.....	1	2	.....	.....	.....	.....	6

NATIONAL HEALTH SERVICE CORPS FIELD STRENGTH BY PROVIDER TYPE, DISCIPLINE, AND URBAN/RURAL STATUS FOR FISCAL YEAR 1998—(AS OF 09/30/98)—Continued

State	State total	Non-obligated Federal	Obligated Federal	NHSC SCH	NHSC LRP	State LRP	COMM SCH	MD/DO	DD	NP	PA	NM	M&BH	Other	Urban	Rural
Ohio	52	.....	.....	16	33	3	.....	39	5	3	.....	5	.....	.....	29	23
Oklahoma	11	.....	.....	5	6	.....	3	.....	1	1	.....	4	7			
Oregon	40	1	.....	14	23	.....	2	21	6	5	5	2	1	.....	4	36
Pennsylvania	98	1	1	18	39	39	.....	51	17	13	15	2	.....	.....	45	53
Rhode Island	13	.....	.....	3	7	3	.....	4	7	.....	1	.....	.....	1 (DH)	12	1
South Carolina	52	1	.....	15	36	.....	.....	33	.....	15	4	.....	.....	.....	6	46
South Dakota	13	.....	.....	5	6	2	.....	6	.....	2	3	.....	2	.....	1	12
Tennessee	33	.....	.....	12	20	1	.....	15	9	6	1	2	.....	.....	18	15
Texas	144	3	.....	29	48	63	1	84	20	15	22	2	.....	1 (NU)	67	77
Utah	47	.....	.....	3	40	4	.....	28	4	2	9	.....	4	.....	12	35
Vermont	2	.....	.....	.....	1	1	.....	.....	.....	.....	1	.....	1	.....	.....	2
Virginia	26	.....	.....	5	18	3	.....	14	4	5	3	.....	.....	.....	.....	26
Washington	96	3	.....	9	67	14	3	46	28	7	12	2	.....	1 (DH)	35	61
West Virginia	40	.....	1	15	11	11	2	14	3	4	17	2	.....	.....	.....	40
Wisconsin	35	.....	.....	11	22	2	.....	17	4	2	4	.....	8	.....	12	23
Wyoming	27	.....	.....	1	26	.....	.....	11	.....	1	9	.....	6	.....	.....	27
Guam	1	.....	.....	1	.....	.....	.....	1	.....	.....	.....	.....	.....	.....	.....	1
Pacific Basin	2	2	.....	.....	.....	.....	.....	.....	2	.....	.....	.....	.....	.....	.....	2
Puerto Rico	23	17	.....	4	2	.....	.....	19	4	.....	.....	.....	.....	.....	4	19
Virgin Islands	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....	.....
Total number	2,439	64	6	533	1,306	508	22	1,326	308	295	364	58	80	8	985	1,454
Total percent	100	2.6	0.3	21.9	53.5	20.8	0.9	54.4	12.6	12.1	14.9	2.4	3.3	0.3	40.4	59.6

Non-obligated Federal = Federal-salaried providers who do not currently have a scholarship or loan repayment obligation.
NHSC Federal obligated = Providers doing long-term training or serving in the USUHS.
NHSC SCH = Providers with a current National Health Service Corps scholarship obligation.
NHSC LRP = Providers with a current National Health Service Corps loan repayment obligation.
State LRP = Providers with a current State loan repayment obligation.
COMM SCH = Providers with a current Community Scholarship Program obligation.
MD/DO = Phsician; DD = Dentist; NP =Nurse Practitioner; PA = Physician Assistant; NM = Nurse Midwife; M&BH = Mental and Behavioral Health.
Other is listed as NU = Nurse; DH = Dental Hygienist; POD = Podiatrist.
Urban = Providers serving at a site in an urban setting; Rural = Providers serving at a site in a rural setting.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 34,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 2000 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

OVERVIEW OF PHYSICIAN ASSISTANT EDUCATION AND PRACTICE

As committee members may be aware, PA programs provide students with a primary care education that prepares them to practice medicine with physician supervision. The first PA program was started at Duke University approximately 30 years ago, and today there are 110 accredited PA educational programs.

Prior to admission, the typical PA student has a bachelor's degree and over four years of health care experience. PA education typically is 25 months in length and includes more than 400 hours in basic sciences, more than 149 hours in behavioral sciences, and more than 535 hours in clinical medicine. PA students also complete more than 2,000 hours in clinical rotations, with an emphasis on primary care. Upon completion of an accredited PA program, PAs must complete a rigorous national certifying exam administered by the National Commission on Certification of Physician Assistants. To maintain their certification, PAs must complete 100 hours of continuing medical education every two years and take a recertification exam every six years.

PAs work in virtually every type of medical and surgical specialty, including family/general medicine, internal medicine, obstetrics/gynecology, pediatric medicine, occupational medicine, and emergency medicine. PAs' primary employment settings include individual physician offices, group practices, managed care organizations, hospitals, and outpatient clinics.

CONTRIBUTION OF PAs AS PRIMARY CARE PROVIDERS

The PA profession has a long standing commitment to practice in our nation's small towns, rural areas, and underserved communities. PAs play a pivotal role in expanding access to primary care services, particularly in medically underserved communities. Data collected in 1998 show that over half of the PA profession is in family/general practice medicine, general internal medicine, general pediatrics, and obstetrics/gynecology. More than a third of the profession practice in communities of less than 50,000 people.

Studies conducted by the Rand Corporation have found that PAs save costs, can perform a substantial portion of the functions in an ambulatory care practice, and are widely accepted by patients. The congressional Office of Technology Assessment studied health care services provided by PAs and determined that "within their scope of practice, physician assistants provide health care that is indistinguishable in quality from care provided by physicians."

CRITICAL ROLE OF THE TITLE VII, PUBLIC HEALTH SERVICE ACT, PROGRAMS

Despite an increase in state health insurance reforms, a reduced rate of growth in health care spending, and the emergence of a new children's health insurance program, a growing number of Americans lack access to primary care, either because they are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured U.S. population increased from approximately 32 million in the early 1990s to an estimated 43.1 million, or 18.3 percent of the nonelderly population, in 1999. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to 2,723 in 1998.

The role of the Title VII programs is to alleviate these problems by supporting access to quality, affordable, and cost-effective care in areas of our country that are most in need of health care services, specifically rural and urban underserved communities. This is accomplished through the support of educational programs that train more health professionals in fields experiencing shortages, improve the geographic distribution of health professionals, and increase access to care in underserved communities.

The Title VII programs are the only federal education programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurses and some allied health professions training has been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to nor does it generate a supply of providers who are willing to work in the nation's medically underserved commu-

nities. That is the purpose of the Title VII Public Health Service Act Programs, which support such initiatives as loans and scholarships for disadvantaged students, scholarships for students with exceptional financial need, centers of excellence to recruit and train minority and disadvantaged students, and interdisciplinary initiatives in geriatric care and rural health care.

TITLE VII SUPPORT OF PA EDUCATION PROGRAMS

Targeted federal support for PA education programs is currently authorized through Section 747 of the Public Health Service Act. The program was recently reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, Public Law 105–392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry.

Public Law 105–392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and operate accredited programs for the education of physician assistants and faculty, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. These goals are accomplished by funding PA education programs that have a demonstrated track record of: (1) placing PA students in health professional shortage areas; (2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs.

The program works. A review of PA graduates from 1991–1999 reveals that 16.5 percent of students graduating from PA programs supported by Title VII are from underrepresented minorities, compared to 7.7 percent of graduates from programs that did not receive Title VII support. In the same vein, 13.5 percent of the graduates who attended PA programs receiving Title VII support during the eight-year period practice in underserved settings, compared to 10.1 percent of graduates of programs not receiving such support during the same period.

Without Title VII funding, many of the special PA training initiatives that are designed to encourage PA practice in underserved communities would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the special, unmet needs of medically underserved areas or disadvantaged students. Nevertheless, the need is very real, and Title VII is critical in meeting it.

NEED FOR INCREASED TITLE VII SUPPORT FOR PA EDUCATION PROGRAMS

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without the Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or the communities in which they attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation.

The supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 1994 report of a workgroup of the Council on Graduate Medical Education (COGME), "Physician Assistants in the Health Workforce," estimated that the anticipated medical market demand and the estimated workforce requirements for PAs would exceed demand. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 47 percent between 1996 and 2002.

Despite the increased demand for PAs, funding has not proportionately increased for the Title VII programs that are designed to educate and place physician assistants in underserved communities. Between fiscal year 1994 and fiscal year 1997, PA program funding went from $6.5 million down to $5.9 million and, as of fiscal year 1997 was restored to $6.376 million. PA program funding was slightly increased again for fiscal year 1998 at $6.398 million and again for fiscal year 1999 at $6.623 million. In 1992–1993, approximately 64 percent of 55 PA programs received federal support, at an average of $143,500 per grant. In 1996–1997, less than half of 77 PA programs reported receiving federal support, at an average of $152,300 per grant. The fiscal year 1998 appropriation provided 42 awards to support the training of approximately 1600 PA graduates.

RECOMMENDATIONS ON FISCAL YEAR 2000 FUNDING

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all the public health agencies and programs when determining funding for fiscal year 2000. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control (CDC) that ensures a prompt response to an infectious disease outbreak, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the cutting edge research discovered at NIH to the patients—through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The critically important programs administered by NIH, HRSA, and CDC are integral components within the nation's public health continuum. One component is not more important than another, and no one component can succeed without adequate support from each of the other elements. The Academy is particularly concerned that any increase for the NIH not be made at the expense of the health professions education program or other public health programs.

The American Academy of Physician Assistants is particularly appreciative of the increases in funding for PA and other health professions education programs that were appropriated during the 105th Congress. However, these increases have not been sufficient to meet the increasing demand for PA graduates and other primary care practitioners in the growing number of medically underserved communities.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the American Academy of Physician Assistants supports HPNEC's recommendation to appropriate $316 million in fiscal year 2000 for the Titles VII and VIII health professions programs. The HPNEC recommendation represents a 4 percent increase over the amount Congress appropriated in fiscal year 1999. Similarly, the Academy requests that the fiscal year 2000 appropriation for the Title VII PA Education Program be no less than $7.072 million, representing a 4 percent increase over the fiscal year 1999 allocation amount.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 2000 appropriations.

PREPARED STATEMENT OF SUSAN SCRIMSHAW, PRESIDENT-ELECT, ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH

Mr. Chairman, I am Susan Scrimshaw, dean of the School of Public Health at the University of Illinois at Chicago and President-elect of the Association of Schools of Public Health (ASPH).

I would like to thank you, Mr. Chairman and members of the subcommittee, for the opportunity to present our statement on the ASPH fiscal year 2000 appropriations requests for PHS programs of primary concern to the academic public health community. You will find a chart at the end of my statement that outlines these recommendations. For now, I would like to highlight some of them.

PREVENTION RESEARCH CENTERS (CDC)

The Congress established the CDC prevention research centers program in 1985 to provide grants to academic institutions to fund applied research designed to develop new and innovative strategies in health promotion and disease prevention. Through this program, the expertise of a number of schools of public health is made available to federal, state and local health officials, community-based organizations and nonprofit organizations. Additionally, the centers serve as sources of education and training for America's next generation of public health professionals. Unfortunately, the funding level for the program has never reached the level that Congress intended when authorizing the program.

ASPH request

CDC currently funds 23 prevention research centers at schools of public health and schools of medicine across the country. Each center has a specific prevention research focus, based largely upon its faculty expertise and geographic location. However, core funding for prevention centers has been decreasing since the program was first funded in 1986 from an average of approximately $800,000 per center to the current year average of approximately $580,000 per center. ASPH requests that the Congress increase the funding for this important program from the current year

level of $13.5 million to $30 million. These funds will be used for the following purposes: To increase the core funding of centers such that the average core award is $1 million (as intended by the Congress) which would allow CDC the flexibility to provide additional funding to centers which have undertaken a more aggressive program; to provide sufficient resources to permit not more than six new, competitively selected centers; and to provide the necessary resources for administration of an expanded program at CDC. Additionally, ASPH requests that the Congress include report language directing that CDC fund the most qualified applications in a peer review process, regardless of geographic location.

It is evident that the research investment in prevention has numerous benefits for the American people. Prevention research promotes healthy behaviors, expands screening for detection of diseases treatable in early stages, offers education in making wise health choices, and encourages community action for programs, policies and practices that can reduce disease risks. Increasing funds for prevention research centers in fiscal year 2000 will enable them to expand community-based interventions further into communities, allowing wider access to lifesaving research and interventions.

PREVENTION RESEARCH INITIATIVE (CDC)

Mr. Chairman, we respectfully request that $100 million be allocated toward a program of competitive extramural research at CDC. This request represents an increase over the President's request of $15 million for the program, but the same as requested by CDC in internal budget deliberations with OMB.

The benefits of population-based prevention are astounding. The Journal of the American Medical Association published a widely accepted article in 1993 that estimates that only 10 percent of all early deaths in this country can be prevented by medical treatment. By contrast, the study found that population-wide public health approaches have the potential to prevent up to 70 percent of these early deaths through measures that target underlying risks, such as tobacco, drug and alcohol use, injury, diet and sedentary lifestyles, violence and environmental factors.

ASPH request

The Association of Schools of Public Health requests that Congress increase the funding for the CDC prevention research initiative to $100 million. Such a program should focus on conducting priority research in the following areas: investigations into the epidemiology of disease, including identification of social and behavioral determinants of illness; studies of means to ameliorate personal, social and environmental factors contributing to disease onset or exacerbation; investigations into the disproportionate disease burden among underserved populations; studies of vulnerable populations with a high disease burden; studies into immunization strategies and of methods for and the cost-effectiveness of population screening programs; and studies into the means by which further decline in physical or social functioning can be prevented in people already ill. Finally, the program would serve to expand the capacity of CDC ("the prevention agency") to bring the benefits of prevention to the millions of Americans at risk for unnecessary early death.

HEALTH PROFESSIONS EDUCATION (HRSA/BHPR)

Mr. Chairman, we are very disappointed that the Administration has recommended zero funding for the public health and preventive medicine programs administered by the Health Resources and Services Administration. If HRSA ("the access agency") is to carry out its charge, then it will need a cadre of well-trained health professionals at the state and local levels to do so. As you know, several government and private sector sources indicate that as many as 80 percent of state and local public health officials have no formal public health training.

The Pew Health Professions Commission, in its 1995 report, entitled Critical Challenges: Revitalizing the Health Professions for the Twenty First Century, concluded that the demand-driven system in health care and health professions practice will result in a surplus of 100,000 to 150,000 physicians in the next century. However, the same study concluded that the demand for public health professionals will increase substantially as managed care organizations seek to hold health care costs down by employing prevention solutions and community-based interventions. This conclusion was further underscored by another study, released last month by the Robert Wood Johnson Foundation: A Growing Excess of Physicians and a Growing Dominance of HMOs.

In 1997, DHHS released a report, entitled The Public-Health Workforce: An Agenda for the 21st Century, which confirmed the Pew Commission's findings when it stated that: "Today our Nation faces a widening gap between challenges to improve

the health of Americans and the capacity of the public health workforce to meet those challenges." The Pew report further states that "the system of care that has emerged in the U.S. is focused primarily on those interventions that deal with treatment rather than prevention. This has led to relatively small investments in broad public health strategies that promote healthy communities and individuals."

ASPH request

Mr. Chairman, ASPH respectfully requests $20 million for public health training and education programs in HRSA. Of this amount, $10 million would be dedicated to funding public health training centers at schools of public health. The total amount, then, would be targeted to: make public health education more accessible; create links between public health education and future trends in the practice of public health; provide education or training for students in practice-based sites instead of solely in the classroom; and develop educational methods and distance-based learning technologies that ensure the ability of the public health workforce to reach underserved populations.

Ensuring that public health training resources remain available to schools of public health will bolster the efforts of these institutions to educate the next generation of public health professionals in a time when population-based prevention efforts are most needed.

CURRENT WORKFORCE DEVELOPMENT (CDC)

According to several public health workforce experts in both government and the academy, as many as 80 percent of the individuals currently working in state or local health departments have no formal education in public health. Furthermore, those same experts estimate that less than 50 percent of the directors of local health departments, many of whom possess MDs, have no public health training. Therefore, a critical need exists to provide these professionals with the most up-to-date training available.

In addition, the recent focus on potential bioterrorist attacks on the United States has led many to question the ability of the current public health workforce to deal with such an emergency. There has not been a case of smallpox, for example, since the early 70s—and few public health professionals are trained to recognize the symptoms of this deadly disease. This lack of formal training in infectious diseases extends to other biological agents such as anthrax, tularemia, boutulinin toxin and plague.

A recent study commissioned by the US Public Health Service, entitled The Public Health Workforce: An Agenda for the 21st Century, identifies the need to employ new technologies for distance learning to the public health field. The report states, "All partners in the effort to strengthen the public health workforce should make maximum use of evolving technologies such as distance learning. A structure should be established to develop an integrated distance learning system building on existing public and private networks and making information on best practices readily available."

ASPH request

The Association of Schools of Public Health proposes that the Congress include an additional $10 million to the CDC Public Health Practice Program Office, to provide for professional workforce development services to public health employees. It is proposed that CDC select not more than five centers based at accredited schools of public health to conduct distance learning and professional workforce development activities. Outcomes of these programs include: conducting studies to determine the skills that will be necessary for public health workers as new threats emerge, including but not limited bioterrorism surveillance and treatments; developing a comprehensive public health training curriculum to be delivered through the internet, or other appropriate mass communication technology; and offering masters and doctoral degree programs to public health workers nationwide through distance learning technologies.

Providing $10 million to CDC to establish up to five centers at accredited schools of public health that focus on providing professional workforce development to public health employees will ensure that current public health professionals have the skills and resources to meet the pressing public health challenges of the next century.

CHILDREN'S ENVIRONMENTAL HEALTH (CDC)

Mr. Chairman, ASPH respectfully requests $8 million for CDC's Center for Environmental Health to allow expansion of program to include an additional five centers that would conduct research and training activities at accredited schools of pub-

lic health to focus on: employing community-based research methods to identify public health problems that most affect children's health; developing and testing interventions aimed at alleviating the most problematic health threats to children; determining the public health aspects of children's interactions with environment; and training the next generation of public health professionals to focus on identifying the causes of the most pressing environmental causes of illness in children.

This proposal builds on the current EPA/NIEHS-led program by placing primary emphasis on identifying children's health threats in the environment and developing population-based interventions to address these threats. The EPA/NIEHS-led program focuses more on the biomedical side of children's environmental health in partnership with long-term strategies to reduce disease burdens. The CDC component will add population-based approaches to the initiative.

Mr. Chairman, providing $8 million to CDC, to expand the current children's environmental health program (which is funded by EPA and NIEHS) to include an additional five centers established at accredited schools of public health, will broaden the scope of the current program to include prevention research that will help protect children from environmental health risks.

ENVIRONMENTAL RESEARCH CENTERS (CDC)

We are delighted with the Committee's support of CDC's environmental research centers. We respectfully ask Congress to appropriate an additional $5 million to expand the research training and regional research activities of the 15 NIOSH Education and Research Centers and an additional $15 million increase in the NIOSH budget to implement the National Occupational Research Agenda (total increase in the NIOSH budget of $20 million). In addition to training occupational health professionals, the ERCs train academic researchers and initiate research programs that meet regional needs, especially through partnerships with regional stakeholders that include management, labor, and academic institutions.

SUMMARY

As we prepare to enter the 21st century, we urge you and members of the subcommittee to renew the long-standing commitment and support to the Public Health Service by increasing funding for agencies that have contributed to making the US health system the best in the world. These public health partners, along with state and local public health agencies and community-based organizations, and this nation's 28 accredited schools of public health, have nurtured and harvested federal investment in improving the health status of the American public. As such, we support the fiscal year 2000 appropriations requests of the following coalitions that have or will testify before your subcommittee:

—Ad Hoc Group for Medical Research Funding
—CDC Coalition
—Coalition for Health Funding
—Friends of AHCPR
—Friends of NIOSH
—Friends of Title V (MCH Block Grant)
—Health Professions and Nursing Education Coalition
—Injury Control and Research Centers Coalition

Mr. Chairman, the requests outlined by these coalitions represent needs assessments that were derived from the views and expert opinions of this country's most respected administrators, scholars, scientists and leaders in the public health sector. I know you and the subcommittee members will take them into serious consideration when marking-up the fiscal year 2000 appropriations bill.

Mr. Chairman, I would like to end my testimony by again thanking and commending you and the members of the subcommittee for supporting PHS programs in general, and academic public health programs, in particular. The latter contribute to our efforts to educate and train public health professionals in the population/community-based approaches to the prevention and control of disease and promotion of health among individuals and communities.

Listed below are the ASPH fiscal year 2000 funding recommendations for programs of primary concern to the academic public health community:

Centers for Disease Control and Prevention

[In millions of dollars]

Prevention Research Centers (PRCs)	30
Prevention Research	100
NIOSH Training (ERCs)	20

Centers for Disease Control and Prevention—Continued

Environmental Research	8
Injury Control and Research (ICRCs)	20
NCHS	110

Health Resources and Services Administration

[In millions of dollars]

Public Health, Preventive Medicine and Dental Public Health	20
MCH Training	20
Health Professions (total)	316
MCH Block Grant (total)	800
HRSA Program Management	136

National Institutes of Health

[In billions of dollars]

NIH (total)	18

Agency for Health Care Policy and Research

[In millions of dollars]

AHCPR (total)	225

PREPARED STATEMENT OF DEB BECK, PRESIDENT, DRUG AND ALCOHOL SERVICE PROVIDERS ORGANIZATION OF PENNSYLVANIA

My name is Deb Beck and I am the President of the Drug and Alcohol Service Providers Organization of Pennsylvania (DASPOP), a statewide coalition of drug and alcohol prevention and treatment programs, practitioners, employee assistance programs, and drug and alcohol associations representing more than 365 organizations, programs and clinics, over 3,000 certified addiction professionals, 1,200 student assistance professionals, and 400 prevention specialists. Thank you for this opportunity to submit testimony in support of increased fiscal year 2000 funding for alcohol and drug treatment, prevention, and research programs in the Departments of Health and Human Services and Education.

Today I am representing the views of DASPOP, the National Coalition of State Alcohol and Drug Treatment and Prevention Associations, which is composed of 27 state-based associations of treatment and prevention providers in 24 states, and the Legal Action Center, a non-profit law and policy firm that represents individuals in recovery from and struggling with alcohol and drug problems and AIDS.

Thank you, Mr. Chairman and members of the subcommittee, for last year's historic increases for alcohol and drug treatment, prevention and research programs and your refusal to cut funding for these services. Providing strong support for alcohol and drug treatment, prevention, and research is essential to maintaining and improving the health and well being of our nation. These programs saves lives and money by decreasing alcohol and drug use, crime, health care costs, AIDS and welfare dependence and increasing employment.

TREATMENT AND PREVENTION NEEDS IN PENNSYLVANIA

Pennsylvania programs have been leaders in developing effective alcohol and drug treatment programs for women, youth, criminal justice offenders, and other underserved populations. However, despite the success of these programs, the annual waiting list for alcohol and drug treatment services in Pennsylvania is approximately 49,000 individuals. These individuals represent only a small portion of the actual number of persons in need of treatment services.

Despite last year's generous increases for the Substance Abuse Prevention and Treatment (SAPT) Block Grant, this year in Pennsylvania we are expecting reductions in alcohol and drug treatment services. Fewer services will be available because reductions in other funding or benefits that have helped to support alcohol and drug treatment services have occurred. Some examples of these funding and benefit reductions include:

—*Reduced Medicaid Coverage*.—Many individuals with alcohol and drug problems have lost their Medicaid coverage which helped to pay for their alcohol and drug treatment. Some individuals lost their coverage due to changes in Pennsylvania law, while others lost Medicaid coverage because of changes in federal law

which made individuals with a primary diagnosis of alcoholism or drug dependence ineligible for SSI and Medicaid. These changes in eligibility have created a funding shortfall of more than $80 million.

—*Reduced Veterans Administration Benefits*.—Capitation of Veterans Administration addiction treatment benefits have caused many veterans with alcohol and drug problems to seek treatment in other, non-VA programs.

—*Reduced General Support Funding*.—Fewer individuals are eligible for Medicaid coverage that pays for general health care services. When individuals without Medicaid enter alcohol and drug treatment and require medical care, alcohol and drug treatment programs pay for the cost of the client's medical care by using general support funds that are not specifically earmarked for alcohol and drug treatment. This reduction in general support funding results in programs relying more heavily on funds dedicated expressly to treatment to provide alcohol and drug treatment services. These dedicated funds include the SAPT Block Grant.

—*Lack of Managed Care Coverage*.—Commercial managed care companies frequently deny coverage for alcohol and drug treatment, forcing individuals and families to seek treatment in the publicly funded alcohol and drug treatment system.

These funding and benefit reductions place increased pressure on the SAPT Block Grant to provide support for alcohol and drug treatment services. Increased fiscal year 2000 funding, especially for the SAPT Block Grant, is necessary in order for Pennsylvania to expand access to alcohol and drug treatment services, which save both lives and money.

Pennsylvania also has developed effective community-based prevention services that reduce the onset of alcohol and drug use among youth and other vulnerable populations. However, decreasing Safe and Drug Free Schools State Grants program funding will adversely impact many of these programs, requiring cuts in prevention services for youth. Supporting programs that focus on school safety are essential, especially given the most recent episode of school violence in Colorado. However, youth across the nation, especially middle-school youth, continue to use drugs at high rates. Increasing funding for effective, community-based alcohol and drug prevention programs is critical, and the State Grants program in the Safe and Drug Free Schools and Communities Act is a vital resource for these services.

RECOMMENDATIONS

For programs to supply these essential services in Pennsylvania and throughout the nation, we need your support. We urge Congress to adopt the following increases in fiscal year 2000 funding for alcohol and drug treatment, prevention, and research programs in the Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Education, and National Institutes of Health. These are wise investments that will provide desperately needed services in communities across the country:

—$1.885 billion for the Substance Abuse Prevention and Treatment Block Grant to continue last year's initiative to close the treatment and prevention gap.

—$255 million each for the Center for Substance Abuse Treatment (CSAT) and the Center for Substance Abuse Prevention (CSAP), including CSAP's High Risk Youth program, to support Targeted Capacity Expansion programs that provide targeted, gap filling services and infrastructure tailored to address specific and emerging drug epidemics and/or underserved populations, and to support the continued translation of research into best practice through Knowledge Development and Application programs.

—$656 million for the Safe and Drug Free Schools and Communities Act program, with any increased funding allocated to the State Grants program to support local, community-based prevention initiatives.

—$338 million for research at the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and $765 for research at the National Institute on Drug Abuse (NIDA).

TREATMENT AND PREVENTION REDUCE ALCOHOL AND DRUG USE AND HAVE PUBLIC SUPPORT

Numerous studies have demonstrated the effectiveness of treatment and prevention in reducing alcohol and drug use. The National Treatment Improvement Evaluation Study (NTIES) evaluated CSAT's demonstration programs and found sustained reductions in drug use. Drug use declined by 51 percent for crack, 55 percent for cocaine, 47 percent for heroin, and 50 percent for marijuana for the 5,700 clients studied one year after completing treatment. NTIES also found a 78 percent de-

crease in violent crime, 19 percent increase in employment, and 11 percent decrease in welfare dependence.

Prevention also has been shown to be effective in reducing use. A 1997 NIDA study found that research-based prevention programs significantly reduce youth alcohol and drug use. A 1995 Cornell University study of 6,000 junior high students in New York State found that students who participate in school-based prevention programs are 40 percent less likely to use alcohol and drugs than those who did not participate.

Treatment has been repeatedly shown to be cost-effective. A 1994 California study found that each $1 invested in substance abuse treatment and prevention saves taxpayers $7; a 1996 Oregon study determined the return to be $5.60 for every $1 invested.

The public recognizes the value of treatment and prevention services. A 1995 Gallup poll found that 77 percent of Americans favored increased spending for alcohol and drug treatment services. Police have echoed the public's support for treatment. In a March, 1996 poll, 300 police chiefs from around the country ranked drug abuse as the most serious problem in their communities—more serious than domestic violence, burglary and theft, or violent crime. Large-city police chiefs have repeatedly identified the shortage of treatment programs as the most serious limitation in their ability to address drug problems successfully.

CLOSING THE TREATMENT GAP IN OUR COMMUNITIES

Access to alcohol and drug treatment does not meet the current need for services. Only 50 percent of the individuals who need treatment receive it.[1] Waiting lists for alcohol and drug treatment are six months long in some regions.

Recent entitlement reforms will shrink existing alcohol and drug treatment and prevention services significantly at a time when more services will be required. Welfare reform has reduced treatment availability by making individuals convicted of drug felonies after August 22, 1996 ineligible for cash assistance or food stamps in many states. Residential treatment programs, particularly programs serving low-income women and children, have relied on the these funds to help support room and board costs of care. Without these funds, treatment availability will decrease.

Welfare reform also requires states to move individuals from welfare to work within a given time period, or a state's federal welfare funding will be decreased. Several national studies have concluded that 16–20 percent of welfare recipients have alcohol and drug problems. This could translate into an additional 400,000—1,000,000 adult welfare recipients needing treatment to move into recovery, off welfare, and into jobs.

Loss of Supplemental Security Income (SSI) support for individuals with alcohol and drug problems also has increased the need for public treatment services. On January 1, 1997, an estimated 200,000 individuals with alcohol and drug disabilities lost their SSI and Medicaid coverage. Less than 60,000 of these individuals have requalified for SSI and Medicaid under another disability. Residential and outpatient programs have relied on Medicaid to provide treatment. These programs now face budget gaps which reduce treatment availability.

INCREASED INVESTMENT IN PREVENTION PROGRAMS REQUIRED

To reverse the trend of increased alcohol and drug use by youth, especially middle-school aged youth, Congress must increase its investment in community-based prevention programs. The "1997 National Household Survey" reported increased drug use by youth, ages 12–17, despite the fact that drug use among the overall U.S. population remained flat between 1996–97. Current illicit drug use increased by 75 percent for youth ages 12–13, rising from 2.2 percent to 3.8 percent. In 1997, 4.8 million youth ages 12–20 engaged in binge drinking, including 2 million youth who are heavy drinkers.

To effectively address this important problem, further expansion of community-based prevention programs must occur. Every adolescent should have access to alcohol and drug prevention services, however this is not the case nationwide. To provide universal access to effective prevention services increased funding of community-based prevention programs is essential.

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[1] Woodward, A., Epstein, J., Gfroerer, J., Melnick, D., Thoreson, R., and Willson, D. "The Drug Abuse Treatment Gap: Recent Estimates." Health Care Financing Review, Vol.18, Number 3. Spring, 1997.

DRUG AND ALCOHOL TREATMENT, PREVENTION, AND RESEARCH FUNDING MUST BE EXPANDED

Substance Abuse Prevention and Treatment Block Grant—SAMHSA/CSAT

The majority of SAMHSA's funding for drug and alcohol treatment and prevention is sent directly to states through the Substance Abuse Block Grant. The Block Grant is the primary source of federal funding for alcohol and drug treatment and prevention services, accounting for over 40 percent of public funding for these services nationwide.

To help meet the pressing need for alcohol and drug treatment and prevention services, we urge Congress to fund the Block Grant at $1.885 billion for an overall increase of $300 million over fiscal year 2000 funding.

SAMHSA/CSAT & CSAP—Balancing the Knowledge Development and Application (KDA) Program with the Need to Target Services to Underserved Populations and Emerging Drug Epidemics

Funding at the Centers for Substance Abuse Treatment and Prevention should be directed toward two major activities: Knowledge Development and Application (KDA) and services capacity expansion for populations at high risk or which have increased need for treatment and prevention services. Targeting service funding allows CSAT and CSAP to meet the evolving needs of communities by providing targeted, gap filling services and infrastructure tailored to address specific and emerging drug epidemics and/or underserved populations (e.g., methamphetamine, heroin, designer drugs, adolescents, specific racial and ethnic groups, ex-offenders, homeless persons, and women on welfare.)

Investment in the application of research findings is also a key Federal responsibility, and CSAT and CSAP, as the lead Federal agencies in treatment and prevention, are singularly equipped to translate research findings into best practices for treatment and prevention programs.

For fiscal year 2000 we urge Congress to appropriate $255 million each for CSAT and CSAP, an $83 million increase for CSAT and a $88 million increase for CSAP, including CSAP's High Risk Youth program.

Safe and Drug Free Schools and Communities Act—Department of Education

As I discussed earlier, research has demonstrated that school-based prevention programs that focus on personal and refusal skills development can significantly reduce alcohol and drug use. The Safe and Drug Free Schools program also provides critical intervention services by supporting student assistance programs that refer students who are beginning to use alcohol and drugs to appropriate services. These early intervention programs, which have no other source of federal funding, are critical to reaching youth at high risk early.

For fiscal year 2000 we urge Congress to appropriate $656 million for the Safe and Drug Free Schools and Communities Act program, a $90 increase over fiscal year 1999, and we recommend that the entire increase be directed into the States Grants program which supports local community prevention programs.

Basic Research—NIH/NIAAA & NIDA

Research into the causes, costs, and "cures" of alcoholism and drug dependence is an important component of our field's continuum. This past year NIDA scientists have observed biochemical changes in the brain stimulated by drug use with Positron Emission Topography (PET) and scientists at NIAAA have been making great strides in genetic research relative to alcoholism. These breakthroughs have demonstrated that alcoholism and drug dependence research hones our knowledge about addiction and improves our ability to treat and prevent it.

We believe more resources are needed to ensure adequate research attention. We urge Congress to appropriate $338 million for NIAAA, a $78 million increase, and $765 million for NIDA, a $162 million increase.

CONCLUSION

Alcoholism and drug dependence continue to be among our Nation's most serious and costly health problems. The programs I have discussed are the first line of defense to protect our children from developing drug and alcohol problems, as well as the funding source of last resort to treat Americans who have already developed these problems. As a society, we must keep these programs strong. Thank you.

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION, INC.

The Brain Injury Association, Inc. (BIA) respectfully requests $15 million in fiscal year 2000 for the Traumatic Brain Injury Act (TBI Act). BIA is the only national, non-profit organization dedicated to improving the quality of life of persons with brain injury and their families. BIA is composed of individuals with traumatic brain injury, their families, and the professionals who serve them. BIA's mission is to create a better future through brain injury prevention, education, research and advocacy. BIA urges your support for funding to continue the critical work being done under the TBI Act. The Act, Public Law 104–166, is the first nationwide attempt to discern the extent of brain injury in this country and to assist states in providing services specific to persons with brain injury.

The TBI Act defines TBI as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. TBI can also result in the disturbance of behavioral or emotional functioning.

Today, TBI is the number one killer and cause of disability of young people in the United States! Motor vehicle crashes, sports injuries, falls, and violence are the major causes of traumatic brain injury. TBI can strike anyone—infant, youth or elderly person—without warning, and often with devastating consequences. TBI affects the whole family and often results in huge medical and rehabilitation expenses over a lifetime.

An estimated 2 million Americans experience TBI each year. About half of these cases result in at least short-term disability, and 50,000 people die as a result of their injuries. Each year, approximately 230,000 persons require hospitalization for TBI (30 percent of which show disabilities a year post injury), and over 1 million people receive emergency medical care for TBI. BIA estimates the cost of TBI in the United States at more than $48 billion annually. Every year about 80,000 people sustain severe brain injuries leading to long term disability. Through the TBI Act, the Center for Disease Control and Prevention (CDC) has estimated that there are 5.3 million persons living with long term, severe disability as a result of brain injury and as many as 6.5 million person living with some form of injury including mild and moderate brain injuries. CDC notes that these are conservative estimates.

The TBI Act was enacted "to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury." Under the law, the Centers for Disease Control and Prevention (CDC) is responsible for activities related to assessing the incidence of traumatic brain injury, conducting prevention research and increasing awareness of TBI; the Maternal and Child Health Bureau (MCHB) under the Health Resources and Services Administration (HRSA), is responsible for implementing a TBI State Demonstration Program; and the National Institutes for Health (NIH) has been delegated the responsibility of conducting basic and applied research and holding a consensus conference.

I. CDC SURVEILLANCE, EDUCATION AND PREVENTION

The TBI Act authorized CDC to support studies in collaboration with State and local health-related agencies to: (1) determine the incidence and prevalence of traumatic brain injury; and (2) develop a uniform reporting system under which States report incidents of traumatic brain injury. To date, the CDC has published TBI surveillance methods and guidelines for public health purposes and funds fifteen states [1] creating a multi-state, uniform reporting system to provide nationally representative data to define groups at higher risk, causes and circumstances of injury, and outcomes of injury. This information is critical in the planning, implementation, and evaluation of programs for preventing TBI and any accompanying disabilities.

CDC's population based surveillance activities have provided the data for the epidemiologists and statisticians to estimate the incidence and prevalence of brain injury in this country. As CDC's estimates become more refined, the numbers of persons sustaining long term disabilities as a result of brain injury are increasing tremendously. Data from 1996 shows that the number of persons with brain injury exceeds 10 percent of all persons with disabilities in the United States. It is frequently noted that there are 54 million Americans with disabilities—yet estimates of persons living with long term severe disabilities as a result of brain injury have increased in the past two years from 4.5 million Americans, to 5.1 million to 5.3 million. These increases are based solely on better data and analysis, not an increase

[1] Alaska, Arizona, Arkansas, California, Colorado, Louisiana, Maryland, Minnesota, Missouri, Nebraska, New York, Oklahoma, Rhode Island, South Carolina, and Utah.

in the actual incidence of brain injury.[2] CDC also estimates, conservatively, that 6.5 million Americans live with some form of disability as a result of brain injury. Improving the accuracy of these estimates by conducting surveillance in several additional states is crucial to understanding the impact brain injury has on the nation's medical and rehabilitative systems and accompanying costs, educational institutions, lost income and productivity, and the immeasurable toll on family members and all persons sustaining brain injury.

CDC can help address the consequences of TBI by expanding patient follow-up registries. There is a strong need to determine long-term disabilities and related problems (e.g. depression, anxiety, unemployment) from TBI; the health and lifelong social services and supports which persons with TBI need, have been referred to, and have received; discover how to predict which TBI patients will need ongoing medical treatments, rehabilitation programs, and other services; and discover ways to prevent secondary conditions and disabilities.

In addition, the CDC is directed to conduct research into identifying effective strategies for the prevention of brain injury, implementing public information and education programs for the prevention of brain injury, and broadening public awareness of the health consequences of such injury. CDC has drafted a brochure for persons with mild TBI who are treated in emergency departments, which discusses potential problems they may encounter and how to identify services. With additional funding the brochure can be widely distributed and other public awareness efforts can be initiated.

For fiscal year 1999, approximately $3 million was appropriated for CDC's work under the TBI Act. CDC has used most of this funding on its incidence and prevalence studies; we respectfully request an increase of $2 million for education and prevention programs. Funding of $5 million for fiscal year 2000 is necessary to continue CDC's surveillance and long-term outcomes work, as well as to implement effective education and prevention activities.

II. HRSA/MCHB TBI DEMONSTRATION GRANTS PROGRAM

Congress authorized the HRSA to provide grants to States for demonstration projects to improve health and other services for persons with traumatic brain injury. HRSA directed the MCHB to administer this program. The TBI Demonstration Grants are intended to help States implement statewide systems that ensure access to comprehensive and coordinated TBI services for the 5.3 million persons with long-term disabilities and their families. Under the TBI Act, these projects are to involve all relevant disciplines, organizations and consumers.

In order to receive a grant, states must make available, in cash, non-federal contributions toward the costs of their programs in an amount not less than $1 for each $2 of federal funds provided under the grant. While a number of states have had difficulty in raising their share before applying for such grants, a significant number of states were able to do so and applied, but insufficient federal funds were available to fund them. BIA expects this to be the case again as states begin in the next few weeks to apply for grants with fiscal year 1999 TBI Act funds ($5 million).

A. State planning grants

In fiscal year 1998, MCHB made twelve planning grants to states in need of assistance in establishing the necessary infrastructure core capacity components before developing an implementation plan.[3] Nine of these states had received planning grants in fiscal year 1997. Awards ranged from $38,000 to $75,000. Four core capacity components were identified as the essential elements in any plan for state implementation of TBI services. These grantees are developing statewide TBI advisory boards; designated state agency and staff position responsible for TBI activities; statewide needs assessment to address the full spectrum of care and services from initial acute treatment through community reintegration for individuals with TBI; and a statewide action plan to develop a comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of the family as well as the individual TBI.

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[2] The incidence of TBI, 2 million per year, has remained relatively constant, however, due to improvements in the nation's trauma systems and medical advances, more people are surviving devastating traumas.

[3] Delaware, the District of Columbia, Illinois, Maryland, Michigan, Nevada, New Hampshire, Oklahoma, South Carolina, Texas, Virginia, and Wisconsin.

B. State implementation grants

MCHB made eleven implementation grants in 1998, to help states move toward systems that assure access to comprehensive and coordinated services for individuals with TBI.[4] The implementation grants require states to establish interagency linkages; education and training for persons with TBI and their families; data collection to track programs, resources and enhance program evaluation; develop materials for low literacy and culturally or ethnically distinct populations; develop a predischarge model to be used in acute care sites in the development of long term resource plans for individuals with TBI; and develop a model to coordinate financial resources to provide services that most effectively meet the needs of persons with TBI.

In fiscal year 1999, $5 million was appropriated for this program. In order to allow new states to apply for planning grants and move participating states into the implementation phase, we respectfully request an increase of $2 million for this program. To maintain the continuity of these projects, it is necessary that $7 million be appropriated for fiscal year 2000.

III. NIH CONSENSUS CONFERENCE AND THE NEED FOR APPLIED RESEARCH BY NIDRR

The TBI Act directed the National Institutes of Health (NIH) to conduct a consensus conference on TBI. In October 1998, the NIH held such a conference regarding managing traumatic brain injury and related rehabilitation concerns. Conference participants evaluated the scientific data concerning rehabilitation practices for adults with TBI. Particular emphasis was placed on rehabilitation of cognitive, behavioral, and psychosocial difficulties associated with mild, moderate and severe TBI. The Conference found recurring themes from a detailed review of the evidence-based scientific evaluations of cognitive and behavioral rehabilitative interventions, but noted that scientific evidence is based on limited studies that need replication, larger clinical trials and more definitive investigation. In essence, the consensus is that more research needs to be done particularly applied research. In addition, it has become clear that extensive research is needed regarding lifelong issues for children with TBI and their families.

The TBI Act had also directed NIH to identify common therapeutic interventions used for the rehabilitation of individuals with brain injuries and to develop practice guidelines for the rehabilitation of traumatic brain injury at such time as appropriate scientific research becomes available. BIA strongly believes that basic brain injury research (i.e. laboratory studies) should be conducted by the NIH, however there is a more compelling need for applied research (using human subjects) which should be conducted through the National Institute on Disability Rehabilitation Research (NIDRR) in the Department of Education. NIDRR administers TBI model systems of care, and with additional funding specific rehabilitation research and training centers and rehabilitation engineering centers can best conduct applied brain injury research in coordination with that program. $3 million is needed for applied brain injury research to be conducted by NIDRR in the Department of Education.

BIA respectfully requests $15 million in fiscal year 2000 for the Traumatic Brain Injury Act ($5 million for CDC, $7 million for HRSA, and $3 million for NIDRR in Dept. of Ed.)

PREPARED STATEMENT OF JERRY BOSWELL, NATIONAL SPOKESMAN, CITIZENS COMMISSION ON HUMAN RIGHTS

Hon. Chairman Specter and members of the subcommittee: The Citizens Commission on Human Rights applauds your decision to hold this historic hearing. Without public scrutiny, the dangers of death and injury from restraint go on unhindered, and the cries of American children who have died in brutal restraints go unheeded. Your courage in opening this issue for possible legislative remedy is most appreciated.

Our organization was established in 1969 by the Church of Scientology and the acclaimed psychiatric critic, psychiatrist Thomas Szasz. Our purpose is to investigate and expose psychiatric violations of human rights. We have extensive experience in investigating tragic deaths in relation to restraints in psychiatric hospitals and other facilities.

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[4] Alabama, Arizona, Florida, Georgia, Iowa, Minnesota, Missouri, New York, North Carolina, Ohio, and Oregon.

Our own investigations have shown that death by restraint is a horrible tragedy, and that it is rarely investigated appropriately by local law enforcement, or prosecuted. In the majority of cases investigated by CCHR, the death was caused by asphyxiation, or bluntly, strangulation. An attached document by our Medical Expert, Moira Dolan, MD, an Austin, Texas Internal Medicine specialist, reviews the medical literature on such deaths, and clearly shows that asphyxiation is the most commonly reported cause (See attached). The last moments of the lives of some of the children our investigations have scrutinized have been particularly horrifying.

ROSHELLE CLAYBORNE

Roshelle Clayborne, a 16 year old resident at Laurel Ridge psychiatric hospital in San Antonio, Texas, became involved in a struggle with staff one day in August, 1997. A government report from the State of Texas (see attached) states: "Staff failed to protect the health, safety, and well-being of [Roshelle] during her restraint and seclusion. [Roshelle] stated several times during the restraint that she could not breath. She also defecated and urinated during the restraint. Within minutes of being given a fifty milligram shot of Thorazine she became 'unresponsive,' 'limp,' 'quiet,' 'still,' 'unconscious,' 'lax.' Despite these atypical behaviors staff failed to respond to her physical and medical needs. [Roshelle's] immobilized body, soiled with feces and urine was placed onto a blanket and transported to locked seclusion. When [Roshelle] was observed she was found in the same position in which she was left. The LVN and a staff member went in to check on her and found her without a pulse and not breathing. CPR was not immediately initiated. An RN who responded to the Code Blue started CPR when she arrived on the scene."

When interviewed by a government investigator, one staff member on the scene of Roshelle's restraint said, "This is the way we do with [Roshelle]—boom, boom, boom—PRN's and restraints and sending her to seclusion room." Other staff also stated that "moving a resident directly from restraint to seclusion was 'routine,' 'procedure,' 'just the next step that's taken,' the 'automatic' thing to do."

The "automatic" thing to do was done to Roshelle's roommate only two weeks after her death. Lisa Allen, also 16 years old at the time, underwent the same restraint by the same workers in the same hospital. As if to prove the idea that their routine was automatic, "Boom, boom boom", Lisa went into restraint, received Thorazine, and was put in locked seclusion. Her parents feared for her life, and once they brought their concerns to us, we forwarded information on her treatment and Roshelle's death to the state of Indiana, where she was from. State workers arrived within days to get her out of the facility and back to Indiana, alive. Her roommate Roshelle had not been so fortunate.

At the end of Texas' state investigation into her death, under a section of the official report entitled PLANS FOR FOLLOW-UP, the investigator wrote, "No plans for follow up. Recomendation [sp] for revocation of license." The hospital appealed the State's attempts to repeal their license, and remains open to this day. The local prosecuting attorney refused to bring criminal charges against anyone involved. This lack of action against facilities and personnel involved is consistent with other similar incidents nationally.

EDITH CAMPOS

A police report from Tucson, Arizona dated February 2, 1998 says that Edith Campos was 15 years old, 5 foot 5 inches, 120 pounds and "slim" the day she died at Desert Hills psychiatric hospital. The report reveals that psychiatric tech Dan Walsh, a 34 year old man, and Edith got into an argument over a personal photograph. After supposedly cursing at Walsh, Edith "raised her fist as if she were going to hit Walsh." What follows is an amazing interaction between a 34 year old adult man and a 15 year old child. "He restrained her [and] placed her on the floor where she was held as she yelled [and] resisted for about 10 [minutes]. After Campos became quiet she was helped into a sitting position. By this time reportee [Mike Segura, the maintenance man] had arrived [and] commented that Campos didn't look good. Nurse Linda Wons was called in [and] found Campos 'trance like.'"

The psychiatric hospital Edith Campos was at remains open, although investigation of sexual conduct by a facility employee has led to the county announcing plans to pull out 38 children whom they had placed there. After a hearing last May to determine if Dan Walsh should face criminal charges over Edith's death, Walsh was let off. So, as in Roshelle's case, no real sanctions were brought about as a result.

PATTERN OF ABUSIVE RESTRAINTS AT A BRAIN INJURY REHABILITATION CENTER

One facility we investigated in 1997–98 was a brain injury rehabilitation center in the Texas countryside owned and run by a psychiatrist. Their use of physical re-

straints of patients is now the subject of a lawsuit by the Texas Attorney General's office (see attached copy). The lawsuit states that at Tangram Rehabilitation Network, "abusive behavior exhibited by the staff included pushing residents to the ground and holding them down, punching and slapping residents in the face, grabbing residents by the hair, and grabbing a resident by the throat to make him spit out what he was eating. Forms of verbal intimidation included threats to "show him who the boss is," telling residents to "suck it up . . . get moving," and "If you tell anybody, it will be worse."

As in many cases, we are concerned that self reports of activities that occur in restraint by hospital employees are exaggerated. In the Tangram lawsuit, a revealing passage states, "In another incident, Employee L revealed that she was having trouble with Client #9 in the shower of the dormitory and she had to restrain the client. Employee L called for help and Employee N arrived first. Employee N took charge of the Client #9's upper body and Employee L restrained the client's legs. Employee L reported that, while Client #9 was being restrained on the shower room floor she observed Employee N grab the client by the hair and strike the client's face on the concrete floor. The facility's report of this incident reflects that Client #9 became a threat to others and was placed in a prone restraint. The report states further that the resident continued to struggle and struck her head. Client #9 sustained bruising and swelling to right eye and a 2″ diameter scrape above eyebrow."

In this case, three employees are facing criminal charges, and the facility is under litigation brought by the state. The difference in this case is that there were detailed and lengthy investigations of the circumstances conducted by trained law enforcement officers. Multiple interviews by law enforcement with staff and residents revealed a pattern of abuse that could be prosecuted. The state was able to gather evidence through these multiple interviews which mirrors the type of data that federal legislation seeks to gather: information on how often restraints are used, and how often deaths and injuries occur as a result of a restraint procedure.

A MONETARY INCENTIVE BEHIND THE USE OF RESTRAINTS

A special report by 60 Minutes on April 21, 1999 showed undercover video footage of the internal workings of a private psychiatric hospital. Workers there used restraints on children for the minor crime of yelling and screaming, and for "behavioral problems", minor troubles hardly worthy of restraint, especially considering that the facility was still in trouble for a recent death of a child in restraint. The workers also discussed the fact that the "negative" aspects of a child's behavior and treatment needed to be highlighted in their medical records, in order to justify their continued hospitalization. Were restraints being used on patients to show a negative course of treatment, requiring longer hospitalization and better reimbursements for the hospital? If so, is this rationale being used in private psychiatric hospitals and other psychiatric treatment centers nationally?

In answer to this question, a report by CCHR International cited Kenneth Clark, M.D., a Harvard College graduate and psychiatrist, who stated, "Regarding reimbursement rates for patients placed in restraints—I know that if they say a patient is uncontrollable the patient is then transferred to the Psychiatric Intensive Care Unit (PICU). The daily rate is higher, so there is a rate increase when the patient is in restraints as the patient obviously needs more intensive care. I know there were instances where the patient was aggravated or provoked to justify the use of restraints and this placement. The staff at the hospital where I worked referred to the practice as 19Mayhem Therapy.' I don't have exact figures but I do know that it cost more than a thousand dollars a day for a patient for this. This estimate is probably on the low side."

A brief scan of the internet turned up two psychiatric rate schedules which prove the point that a psychiatric hospital can make more money for a patient that restraints are used on. One hospital advertised standard care as costing $550 to $575 per day, while Intensive care cost $650 per day. Another facility promoted the fact that in their psychiatric intensive care unit, restraints and seclusion are included in their treatment.

An employee from a Texas residential psychiatric treatment facility stated the following during an interview: "You keep up the incident reports [reports of restraints used or other major incidents that have occurred] because the insurance company wants to know the progress. You have a catch 22 in that the insurance won't keep the client there if there isn't some progress, so you have to show some progress, and then if you have a lot of agitation, then you can say that because he has become more difficult, his care has gone from $5,000 to $9,000 per month. That was done."

The fact that there may be a correlation between the use of restraints and seclusion, and reimbursement at a higher rate for such patients, needs to be seriously

examined and if need be, amendments made to the proposed legislation to deter such practices.

CONCLUSIONS

Our investigations and research has led us to conclude that any legislation to be effective in halting the use of "deadly restraints" would include the following elements:

1. Reporting by each facility to the government of the numbers of times restraints, chemical restraints, and seclusion are used to control patients.
2. Reporting by each facility to the government each time an injury or death occurs in restraint or in relation to the prior use of a restraint.
3. All deaths and injuries related to restraint should be thoroughly investigated by law enforcement officers. Law enforcement should be called in immediately to preserve the "chain of evidence", and the scene should be treated as a crime scene for purposes of investigation.
4. Facilities should be legally responsible for ensuring the full training of their staff in proper restraint techniques. Restraints should be limited to use only in last resort emergencies to prevent assault or harm. Facilities which do not comply with these measures should be held criminally liable for deaths or injuries that occur in restraint.
5. The prescribing of "standing orders" or "PRN's" by psychiatrists for restraint, chemical restraint, or seclusion should be specifically outlawed.
6. The connection between the use of restraints and increased reimbursements for psychiatric facilities should be explored, and the use of restraints in order to increase reimbursement levels should be specifically outlawed.

Once again, I would like to express my gratitude to Senator Specter and the rest of the Subcommittee members for bringing up this vitally important topic for a hearing. Your efforts and the results of your hearing will go a long way toward ending the psychiatric abuse of thousands of Americans in the form of "deadly restraints."

PREPARED STATEMENT OF THEODORE PASINSKI, PRESIDENT, ST. JOSEPH'S HOSPITAL HEALTH CENTER

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to present this testimony. I am Theodore Pasinski, President of St. Joseph's Hospital Health Center in downtown Syracuse, New York. St. Joseph's is a non-profit 431-bed hospital and health care network providing services to Onandaga County and to patients from 15 surrounding counties. St. Joseph's is best known for its ranking as the #1 hospital in New York State for open heart surgery in terms of lowest overall mortality rate. We are very proud of this ranking, which we have held for three consecutive years. What many people do not know is that we are also the largest hemodialysis center outside metropolitan New York. My statement today is focused on these two areas of expertise at St. Joseph's and how we plan to initiate a chronic disease management model that will benefit our current patients with heart and kidney disease and enhance the quality of life for at-risk patients in the region. We see this initiative as one with not only health enhancement benefits but also with significant positive economic implications for the community and the region. I will explain this dynamic in general terms for the Subcommittee.

St. Joseph's provides over $7 million in bad debt and charity care to our service region. This comes to about 4 percent of our operating budget. This number has steadily risen over the years and we feel it will continue to do so unless some dramatic steps are taken. In order to increase access to patients who are underserved and at-risk for disease, we have implemented a program of "patient-centered care." We believe we achieved our #1 ranking for cardiac care through this process, which employs a secondary prevention model for disease management. By applying a multidisciplinary team approach to heart disease and preparing patients before surgery and rehabilitating them after, we have reduced mortality rates as well as the number of second hospitalizations. We have done this to improve the overall health of an underserved and underinsured patient base, but also for practical financial reasons. While our rehabilitation and education programs for our cardiac patients are largely unreimbursed, we are rewarded by having to perform less expensive charity care on patients who would typically end up back in the hospital without disease management.

Recognizing that early assessment is important to reducing the number of expensive treatments required later in life, St. Joseph's instituted a Wellness Place at a local mall so that people could stop in at their convenience. The Wellness Place pro-

vides free, general health screenings such as blood pressure readings, cardiac and diabetes risk assessment, counseling and patient education and seminars. Last year, approximately 15,000 people used the Wellness Place. Nearly 1000 of these people were determined to be at risk for heart disease, diabetes, or vascular problems. These individuals were offered follow-up services intended to change lifestyle, such as nutritional counseling, smoking cessation, exercise programs and other similar regimens. They were also offered a choice of primary care physician if none was identified. This is all done at considerable unreimbursed expense to St. Joseph's but with the knowledge that a great deal of money will be saved in the long run—for the patient, the Medicare system and the hospital. The most dramatic economic implications I mentioned are encompassed within this concept—but not all. At risk patients are working people who may lose jobs if their disease progresses. It is important to realize, however, that patients with diagnosed diseases or who have congestive heart failure, may still work and lead productive lives if an effective disease management program is initiated at the earliest stage possible.

Assessment is the first line of defense in chronic disease management; but, there are many other factors involved after this step is taken. A program for management of disease must adequately educate patients and then foster a sense of individual responsibility for the importance of following prescribed regimens. This takes a great deal of initial monitoring and time spent with patients by telephone, at community health centers, and in the home. This also requires coordinated community participation by physicians, nurses, pharmacists, physical therapists, educators, behavioral specialists and even employers.

Diabetes, leading to kidney disease and kidney failure, is the most expensive disease in the country. The second most expensive, and #1 admitting diagnosis for Medicare, is congestive heart failure. The U.S. spends more than $7 billion annually in Medicare dollars for these diseases. The clinical relationship between chronic kidney failure and heart disease (e.g., high blood pressure) requires similar early intervention techniques as well as later management, treatment, and rehabilitation. Utilizing resources already developed and in place for our cardiac rehabilitation program, St. Joseph's is proposing to further develop a chronic disease management program focused on hemodialysis. Combining resources in this way will be cost effective and has the potential to radically change the management of kidney disease.

The specific objectives of the program will begin with early identification. Timely referrals to a nephrologist can be improved so that more aggressive treatment can be initiated to prolong kidney function and allow better preparation of the patient for dialysis. Second, we will identify, investigate, evaluate, and implement technology that will promote in-center self care and home hemodialysis modalities. Third, we will utilize the St. Joseph's Cardiac Rehabilitation Model for the renal patient. This model will emphasize education and exercise with the goal of improving the percentage of patients that stay employed, reduce frequency and length of hospitalizations, and improve patient acceptance of and control over disease processes. The ultimate goal of the renal patient and the health care industry is to have renal patients lead a "normal" life. Currently, kidney transplantation is the modality that is most associated with that goal.

Our history of service and specialization in the areas of cardiac and kidney disease has proven that there is a demonstrable need for a chronic disease demonstration in these areas for the Central New York region. The demonstration will involve relationships and initiatives in Dialysis, Cardiac Care, Home Care, and Wellness. What we lack at this point, is a facility that can be shared by both cardiac and dialysis patients. Our current dialysis facility, the largest outside the New York Metropolitan area, is woefully inadequate in every way. The facility was originally built as a modular, temporary, unit over 20 years ago. We now treat our overload of patients in the hallways and have legitimate safety concerns that come with overcrowding and questions as to the future structural integrity of the plant itself. We have not replaced this facility for financial reasons but, fortunately, have been able to treat patients satisfactorily. We have three satellite clinics in the region, which are also operating at capacity. Our goal is to implement our demonstration program in an on-campus facility that will provide the space needed for dialysis, exercise facilities, classrooms, meeting rooms, examination rooms, and nurse and allied professional training space. Training of personnel is an important aspect of implementing an innovative chronic disease model.

The two-story facility, equipment and program operation will cost approximately $12.5 million. Last year, St. Joseph's received a $750,000 Department of Housing and Urban Development Economic Development Initiative Grant. St. Joseph's seeks additional Federal partnership grant funding of $4.3 million that will also cover start-up-operating costs. We estimate, based on our current services, that our oper-

ating budget will exceed $5.5 million per year. St. Joseph's will provide, through private sources, the remainder of the estimated total.

We recognize the magnitude of this request but believe wholeheartedly that this facility, and the implementation of our chronic disease management model will repay this initial investment many times over in terms of Medicare savings and in terms of providing a national model for replication across the country.

Thank you.

PREPARED STATEMENT OF SPENCER FOREMAN, M.D., PRESIDENT, MONTEFIORE MEDICAL CENTER, THE BRONX, NEW YORK

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony for the record on the Montefiore Medical Center in the Bronx, New York and the exciting new Children's Hospital at Montefiore that we are developing.

THE BRONX

The Bronx has a population of 1.2 million residents, placing it among the top 10 largest cities in the United States. Approximately 400,000 of those residents are children. Neighborhoods in the Bronx rank among the poorest in the nation. Thirty percent of residents in the Bronx are on some form of public assistance and/or Medicaid (31 percent). Over one-quarter of the residents have incomes under $10,000 annually and sixty percent have annual incomes below $30,000.

The Bronx population is largely composed of historically underserved and uninsured minorities. Three-quarters of the Bronx population are non-white—28 percent African American and 50 percent Hispanic. The Bronx is among the nation's most underserved urban areas with sociodemographic and health status indicators that underscore its need for health services. Those health and social indicators include:

—An infant mortality rate of 12:1 which is among one the nation's highest ratios;
—Rates of teenage pregnancy and low birth weights that are higher than the proportions for the City and nation;
—The incidence of asthma is six times greater than the national average; and,
—The lack of industry and a strong economic base leaves the borough with extreme housing problems, drug abuse and crime, all underlying problems of poverty and unemployment.

MONTEFIORE MEDICAL CENTER

Established over 100 years ago as a chronic care hospital, Montefiore has become a critical resource in addressing the health and social needs of the residents of the Bronx. Today, the Montefiore Medical Center system is a four hospital, 2,326 bed system with two skilled nursing facilities, a home health agency, nine community based primary care centers and a range of other outreach services operating in the Bronx and surrounding communities. This public/private health system provides more than one-third of all inpatient acute care, over 42 percent of all tertiary care, and $50 million in uncompensated care annually.

Montefiore Medical Center was the first hospital to create a community-oriented care program in the late 1960s and early 1970s to meet the needs of underserved residents in the Bronx. MMC has traditionally been a critical element in successfully addressing the social, health and physical well being of those residents.

The Medical Center strives for excellence in patient care, medical education, scientific research and community services. Staff and faculty at MMC practice "family-centered care," working with families to promote health, prevent diseases, and alleviate the burden of illness.

In 1995, Montefiore Medical Center performed an extensive review of the health of their population, specifically children. The study revealed that children in the Bronx are among the City's most needy, with rates of low birth weight, infant mortality, HIV infections and other reportable diseases which rank among the City's most disadvantaged. It also revealed that hospitalization rates for children (0—19 years) in the Bronx are excessive at 65 admissions for every 1,000 persons—nearly twice the average of more affluent areas.

The study also demonstrated that child health programs at MMC are at great risk for the future. While MMC offers a comprehensive array of child health, prevention and education services through a network of inpatient, outpatient, and community programs and facilities, these programs are fragmented and uncoordinated. The four-site program is hard to sustain, and utilization declines (due to managed care) threaten the viability of the system. It was determined that many inadequacies

exist due to the limitations of the physical environment. Existing programs and services at MMC lack focus for the specific needs of children and lack child and family-friendly elements.

Among the four hospitals, inpatient services for children are inadequate and fragmented. Ambulatory services for children are scattered throughout the system and are not well housed, and primary and specialty ambulatory services are not adequately articulated to meet the health and related needs of children. In addition, there are no existing ancillary services specifically designed for children. Finally, the fragmented nature of existing children's services makes it increasingly difficult to staff the four-site program. Rather than having a critical mass of pediatric primary and specialty care in one location, this expertise is dispersed throughout the multisite system, making departmental cooperation and consultation difficult and staff retention very challenging.

It is clear that a restructuring and consolidation of services for children at MMC must take place to ensure the livelihood of the hospital as well as the longevity of children's health services in the Bronx.

In response to this crisis Montefiore has embarked on a comprehensive initiative to tackle the daunting task of consolidating all of our children's services into a central location—the Children's Hospital at Montefiore. The new Children's Hospital will serve as a "hub" of our child health initiative—eliminating fragmentation within the existing child health network, enabling the provision of services in a more direct, cost-effective manner and enabling MMC to better and more efficiently address the ever growing health needs of the children in the Bronx.

THE MONTEFIORE CHILD HEALTH INITIATIVE

The traditional model of children's hospitals is designed for and focuses on chronic care. There has been very little preventive, supportive or specialty care at children's hospitals. With the more sophisticated understanding of childhood illness, the resulting need for advanced care, and with the increased understanding of the connection between an individual's health status and his/her lifestyle and family life—a new model of children's hospitals has emerged.

The Montefiore Child Health Initiative, comprised of both the child health services within the existing Ambulatory Care Network and the Children's Hospital, is a unique example of a modern and aggressive approach to the provision of comprehensive children's primary and specialized health care services.

The Montefiore Child Health Initiative proposes a unique model of care that will assure MMC's continued leadership in the provision of health care and related services to children in the Bronx and surrounding areas. That proposal includes:

A New philosophy of family centered care

At Montefiore Medical Center we believe that the well-being of children is dependent upon the understanding and participation of the family. We promote a respectful, collaborative partnership with the families of our patients, relying on their expertise as the primary source of strength and support for their children. We work with families in designing individual health care and general services, facilities, research, and medical education, respecting their needs, beliefs, culture, values, and knowledge. We value families as central to a child's health and are committed to supporting them in this vital role.

An integrated child health network

The establishment of a child health network, which builds on the existing services available through the Ambulatory Care Network, is a necessity in the rapidly changing environment in the Bronx. The Montefiore Child Health Initiative will ensure that the Integrated Child Health Network provides each child with: access to high quality primary and specialty care; effective connections and communication between existing primary and specialty care services/providers; cohesion among the different parts of the network to ensure a full spectrum of child health and related services; access to the secondary and tertiary services at the Children's Hospital so that children and families will have the option of receiving care in an organized, cost effective and accountable system of care.

The Montefiore Child Health Initiative will provide the consolidation and coordination necessary to effectively and efficiently provide a full range of services for the children and families of the Bronx.

The network aspects of the Initiative will play a key role in ensuring that a full continuum is and remains available for children and their families through the existing impressive array of services throughout the Bronx, including:

—3 hospital outpatient departments, providing primary and specialty care and special programs for children;

—30 ambulatory care sites—receiving over 300,000 visits annually;
—21 school based health clinics—providing services to over 11,000 children annually;
—The New York Children's Initiative—an innovative outreach care programs for homeless children providing care to over 6,300 children annually; and
—An extensive base of privately practicing pediatricians throughout the Bronx and Westchester.

The "front door" to the planned Children's Hospital, the core of the Montefiore Child Health Initiative, is through any one of the affiliated ambulatory care sites in our network. Within the network each child will have an identifiable primary care provider responsible for their care. Any site in the system will have the ability to assess the need for specialty services and to provide those services and consultations on-site or through referral. There will be constant communication between the primary care providers in the community and the specialty care providers at the Children's Hospital or in the community.

The network currently offers specialty services specifically geared to meet the special health and social service needs of children in the community. It is critical to note that these programs do not simply target health needs. They also address some of the underlying economic and social issues that cause illness in children by providing prevention and education services for at-risk youth and families in the Bronx. Those existing special services include:

—Child Abuse Center;
—Pediatric Resource Center;
—Child Health and Safety Initiative;
—Ambulatory care to adolescents with HIV infection;
—A nationally recognized mobile lead screening and safe house program;
—School-based health program providing direct medical services at 21 schools in the community;
—A drop out prevention program;
—Outreach to and prenatal/child care services to pregnant women who are either HIV infected or at-risk for infection; and,
—Community redevelopment/commercial revitalization.

Pediatric Asthma Center

A dedicated center for the diagnosis and treatment of childhood asthma is a major focus of the Montefiore Child Health Initiative. The concept of the Pediatric Asthma Center stemmed from the disturbing statistics about childhood asthma in the Bronx:

—Almost 9 percent of children in the South Bronx have asthma (4.3 percent nationally).
—African American children are three times more likely than white children to be hospitalized for asthma, and four to six times more likely to die from it.
—Rates for Latino children are also higher than those for white children.
—More than five times as many children in the Bronx are hospitalized for asthma compared with national rates.
—In the South Bronx, the rate is 7.5 times the national rate, and more than twice the rate of New York City overall.

The Pediatric Asthma Center will establish a state-of-the-art clinical and educational resource center as well as a community-wide network of services for children and families linked directly with schools and day care programs. The Center's services will provide school-based education and pediatric care for children with asthma, and will serve as a hub for a network of diagnostic and clinical services located in Montefiore's Integrated Child Health Network. Schools and day care centers will be linked to the Pediatric Asthma Center as well as a local network primary care site for services, training and educational programs. State-of-the-art technology, including diagnostic equipment and computer links for clinical evaluation, and support for school-based health care and education, will be key components of the Pediatric Asthma Center.

A new children's hospital

The Children's Hospital will provide the critical connection between the providers of children's health services in the Ambulatory Care Network. It will serve as the hub of the entire Montefiore Child Health Initiative.

The new hospital will not stand alone but will be connected to a tertiary care center. The hospital will be programmed and staffed specifically with the special needs of children and families in mind. Those special features and services include:

—State-of-the-art pediatric emergency room;
—Medical and surgical subspecialty ambulatory clinical modules designed specifically for children;

—A short stay "Day Hospital";
—Family support services;
—Diagnostic and treatment services;
—Age appropriate units specifically designed to care for the individual needs of infants, school age children, and adolescents;
—A state-of-the-art Pediatric Critical Care Unit designed with adequate space for parents to stay with their child with specialized activities such as dialysis and transplant technologies;
—All single occupancy rooms will have parent sleep-in accommodations;
—A playroom on each unit with age appropriate toys, staffed with child life professionals to assist in the developmental needs of children;
—School facilities are available and specially designed to meet the needs of each age group;
—Liaison child psychiatry services; and,
—Medical information stations on each unit.

Carl Sagan Discovery Center

In honor of the memory of Carl Sagan, whose lifelong mission was to help children reach their fullest potential through an understanding of science in all its aspects, the Children's Hospital at Montefiore will create a "Carl Sagan Discovery Center" within the hospital. The Sagan Discovery Center will be a place where children can learn about their bodies, their world and the universe around them while being treated at The Children's Hospital at Montefiore. As such, the Sagan Center will be an integral part of the concept of "family-centered" care that is the hallmark of the Children's Hospital. Through a variety of innovative exhibits and learning tools, the Sagan Center will allow children and their families to learn more about their illnesses and treatment, the workings of the human body, life on earth throughout the ages, and the mysteries of the cosmos.

The Carl Sagan Discovery Center will utilize interactive displays, the Internet, and specialized scientific equipment to provide these learning experiences. This equipment will include a telescope on the roof of the building, which will enable children to explore the wonders of solar system from their rooms; headphones which will afford children the opportunity to hear the "winds" of Mars via a microphone on the planet's surface; and computer technology which will allow children to take "virtual trips" to anywhere in the universe, as well as allow them to talk to fellow patients and other children.

The implementation of the Montefiore Child Health Initiative will elevate the quality and scope of primary and specialty health care services to children and their families in the Bronx.

Montefiore Medical Center, with our 100 year tradition of community service and community-based health care programs, is uniquely qualified to implement and operate the Montefiore Child Health Initiative which could serve as a national model of how complete health systems can adapt to and address the very unique health and social needs of today's inner-city, minority, children.

Montefiore Medical Center looks forward to developing relationships with the federal government to make this plan a reality and to serve as a model to other cities and hospital systems.

FUNDING/BUDGET SOURCES

The new Children's Hospital and related facilities will cost $116 million for capital construction. Our federal request is $20 million of which $2 million was provided in last year's Labor, HHS and Education Appropriations Bill.

PREPARED STATEMENT OF EUGENE PRITCHARD, PRESIDENT, CONDELL MEDICAL CENTER, LIBERTYVILLE, IL

Mr. Chairman, thank you for the opportunity to present this testimony for the record regarding the proposed Regional Center for Cardiac Health Services at Condell Medical Center, in Libertyville Illinois.

As you may know, in the United States today, cardiac diseases are the number one killer of men and women. Everyday, more than 2,600 Americans die of cardiovascular disease, an average of one death every 33 seconds. Among both men and women, and across all racial and ethnic groups, cardiovascular disease is the number one killer in the United States. More than 960,000 Americans die of cardiovascular disease each year, accounting for more than 40 percent of all deaths nationally. In 1998, cardiovascular diseases cost the nation an estimated $274 billion in medical expenses and lost productivity, including more than $50 billion in direct

Medicare and Medicaid expenditures. It is expected that that figure will increase to $286.5 billion in 1999.

Over the last 20 years there has been a dramatic increase in the indicators of prevalence of heart disease and stroke, particularly among Americans over age 65—an age group that is now about 13 percent of the U.S. population and will constitute over 20 percent by year 2010. Currently, almost 10 million Americans aged 65 years and older report disabilities caused by heart disease. Of the nearly 5 million patients afflicted with heart failure, 75 percent are older than 65 years of age.

Cardiovascular diseases are the most common cause of death in Illinois, accounting for an even higher mortality rate than on the national level. According to the National Center for Health Statistics, Illinois had the 10th highest 1995 death rate for heart attacks, stroke and other cardiovascular diseases in the nation, accounting for 101.7 deaths per 100,000 population. Illinois also had the 12th highest rate of total cardiovascular diseases in the nation, at 203.7 deaths per 100,000 population.

In Lake County, IL, these statistics have even more profound implications. Today, the County has a higher incidences of heart disease, cardiovascular disease and chronic obstructive pulmonary disease than the State of Illinois as a whole. In fact, Lake County had 4.6 deaths per 100,000 population from congenital anomalies versus Illinois' 4.2 deaths per 100,000.

With a total population of 540,000, Lake County has a potential for 4,452 cardiac catheterizations annually. Currently, there are four institutions with catheterization labs in Lake County with a combined total volume of only 1,675 or 38 percent of the potential volume, leaving a distinct cardiac health service need in the region. A primary reason for this discrepancy is that many patients are referred out of Lake County for interventional services currently unavailable anywhere in the County. In fact, some patients are forced to travel 90 minutes and more to obtain appropriate cardiac care.

With the region experiencing a 35 percent population growth through 2010, the need for an expanded primary and specialty health services infrastructure, including comprehensive cardiac care, is evident.

The United States Congress recently announced its increased commitment to meeting and countering the many threats that cardiovascular diseases pose to the national health care system. In its fiscal year 1998 Report on Labor, Health and Human Services, and Education Appropriations, this subcommittee articulated the need to develop an "integrated, comprehensive, and nationwide program that could effectively target cardiovascular disease and its risk factors." We here at CMC are taking steps to do identify the risk factors and implement a comprehensive program that will provide, education, prevention, diagnosis, specialty care, surgical care and rehabilitative cardiac care for our patients.

Since 1927, Condell Medical Center (CMC) has been a highly respected comprehensive community health care, prevention and education resource for Lake County, Illinois. The Medical Center has grown from its origins as a 12-bed country hospital to a technologically sophisticated 190-bed acute care medical center with affiliated health care and educational service facilities strategically located throughout Lake County.

Condell Medical Center was the first institution in Lake County to establish a cardiac rehabilitation program in 1978. Since then, the Medical Center has run a basic cardiology program including diagnostic and rehabilitative services at its main campus in Libertyville, IL. It has also provided emergency cardiac care at its main campus and its affiliated acute care centers located throughout the northwestern Lake County region. Currently, acute care centers are located in Buffalo Grove, Vernon Hills, Gurnee and Round Lake Beach. Condell affiliated medical offices are located in these centers in addition to other medical office buildings located in Lake Villa, Grays Lake and Mundelein. A focus on primary care physicians has enabled CMC to manage the medical needs of a large population of patients which has contributed to the success of its entire cardiovascular program.

Condell offers comprehensive care to area residents from the initial onset of the disease through recovery and return to daily routine, including:

DIAGNOSTIC CARE

Opened in 1996, Condell's new centralized Cardiology Department began to offer diagnostic cardiac catheterization services to area residents. One of the first fully-digital cardiac catheterization facilities in the nation, the laboratory aids Condell cardiologists in making a more thorough diagnosis of a patient's heart status. This permits faster clinical decisions, increased continuity of care and less patient stress.

INTENSIVE CARDIAC CARE CENTER

CMC currently operates an Intensive Care Unit with staff trained to provide optimal patient care to those with life-threatening illnesses. Monitoring equipment links patients with nursing staff. The Total Care Team, through its interdisciplinary cooperative efforts, handles the most critical situations in an efficient, well-organized manner to produce the most effective results for the patients.

In the cardiac care program at CMC is primarily comprised of non-invasive diagnostic and rehabilitative care. The Medical Center referred patients in its primary and secondary service areas to other outlying hospitals for specialty cardiac surgical services. In 1997 and 1998 a total of 240 and 343 patients respectively were referred directly from Condell for interventional cardiac procedures.

The practice of referring patients for care interrupted the continuity of care, increased the health risk to the CMC patient, inconvenienced the patients and their families and broke the chain of care between the patient and their primary care physician. Additionally, the cost of care for those patients who are referred increases significantly due to transport costs, repetition of certain diagnostic tests, physician and nursing assessment during the patient admission to the tertiary hospital.

In 1996, CMC established its Cardiac Catheterization Lab providing diagnostic cardiac catheterization services as the first step in the establishment of a regional center for cardiac health services. The catheterization lab established a quality care program with comprehensive peer review process and outcomes measurements.

With the establishment of the catheterization lab in 1996 and the resulting increases in demand for services in 1997 and 1998, it became very apparent that the patients of Lake County have chosen CMC as the hospital-of-choice for their cardiac care.

Today, cardiovascular disease represents 20 percent of all CMC's hospital admissions. In 1998, CMC ended the year with 697 catheterizations, the largest market share in Lake County. In addition, the Medical Center referred 191 patients to other facilities for open-heart surgery in 1998. When the proposed cardiac care center opens, it is expected that the number of cardiac care patients will increase significantly placing additional stress on Condell's ICU, surgical and ED infrastructure.

The addition of a comprehensive cardiac health program including an open-heart surgery and angioplasty program will enable CMC to fulfill its mission of providing a full spectrum of cardiac care.

THE REGIONAL CENTER FOR CARDIAC HEALTH SERVICES AT CONDELL MEDICAL CENTER

In response to the critical need for comprehensive cardiac health services in Lake County, Illinois and the surrounding region, Condell Medical Center proposes to establish the "Regional Center for Cardiac Health Services."

The Regional Center for Cardiac Health Services at Condell Medical Center is being developed as a dynamic, multi-faceted facility designed to bolster the Lake County region's ability to deal with the numerous faces of the cardiac threat in an innovative and integrated fashion. The RCCHS will provide a full suite of cardiovascular services including emergency, surgical, diagnostic, education, prevention and rehabilitation.

This Center, which is part of Condell Medical Center's planned institution wide expansion project, will build upon existing cardiac expertise at the Medical Center and create a full service regional center that will include:

—Cardiac Catheterization Lab (diagnostic and interventional cardiac cath)
—Echocardiography
—Stress Testing
—Cardiac Rehabilitation
—Cardiac outpatient monitoring
—EKG
—Pediatric Cardiology
—Cardiac ICU
—Surgical
—Prevention and Education
—Rehabilitation

The new Center will accommodate increased volume expected from the expanded cardiac programs, the Emergency Department and the primary and secondary service areas.

The proposed program will:

—Be clinically effective, using an interdisciplinary approach with input from surgeons, cardiologists, ancillary professionals, nurses, administration and importantly, patients.

—Facilitate continuity of care from admission through discharge and after-care in the home and rehabilitation.
—Enable cardiologists to maximize patient care through decreased morbidity and mortality through the use of interventional cardiac procedures and on-site open-heart surgery services.
—Provide additional suites for use in open-heart surgeries.
—Reduce referrals out of CMC and Lake County, allowing closer "home care."
—Provide comprehensive cardiac care 7 days a week, 24 hours per day.
—Locate all cardiac services adjacent to one another for increased patient convenience and improved medical efficiency.

Key components of the proposed Regional Center for Cardiac Health Services include:

SURGICAL

Condell Medical Center will provide for the first time in Lake County open heart surgery capability. It will provide suites for use solely as open heart surgery suites which will co-exist within the expanded surgical center.

EDUCATION & PREVENTION

Another aspect of the proposed Regional Center for Cardiac Health Services at Condell Medical Center will be the education and prevention programs. This will entail expansion of the existing Health Promotions Program and Cardiac Rehabilitation Program. In addition, opportunities for the development of specialty services will be evaluated and implemented.

REHABILITATIVE CARE

A key element of the Regional Center for Cardiac Health Services at CMC will be an expanded Cardiac Rehabilitation Program, conducted at Centre Club. The Centre Club is the on-campus health and fitness facility at CMC. This program helps cardiovascular patients return to a safe, healthy and active lifestyle. This two-phase program combines education with individualized exercise prescriptions, which are closely monitored by highly trained staff members.

As a key part of this initiative, CMC will also add a second rehabilitation program off campus at its Gurnee facility.

The establishment of this center is also a critical component in the Medical Center's goal to become the County's first tertiary care center. Other components of that goal will be becoming a level I emergency department, becoming a level I intensive care unit (ICU), and becoming a level III OB/GYN facility.

Condell Medical Center is seeking $7.5 million over two years for the implementation of its Regional Center for Cardiac Health Services. This proposed federal partnership in conjunction with the CMC financial commitment of $72.8 million will provide significant returns on the federal investment through faster and more effective treatment while helping to reduce the significant costs associated with cardiac related illnesses in the area.

The proposed Regional Center for Cardiac Health Services will serve as a national model for the provision and effective management of comprehensive cardiac care in a single location for an at-risk population.

This partnership, in conjunction with the CMC financial commitment of $72.8 million, will provide significant returns on the federal investment through faster and more effective treatment while helping to reduce the significant costs associated with cardiac related illnesses in the area. It will also help to reduce the very real costs associated with cardiac related illnesses in the region.

Again, Mr. Chairman thank you for the opportunity to submit this testimony for the record. We look forward to working with the subcommittee as it strives to implement an effective system for addressing the complex issue of cardiac care.

LOW INCOME HOME ENERGY ASSISTANCE PROGRAM (LIHEAP)

PREPARED STATEMENT OF THE AMERICAN PUBLIC POWER ASSOCIATION

The American Public Power Association (APPA) is the service organization representing the interests of the more than 2,000 municipal and other state and locally owned utilities throughout the United States. Collectively, public power utilities deliver electric energy to one of every seven U.S. electric consumers (about 40 million people) serving some of the nation's largest cities. The majority of APPA's member systems are located in small and medium-sized communities in every state except

Hawaii. APPA member systems appreciate the opportunity to submit this statement in support of fiscal year 2000 appropriations for the Low Income Home Energy Assistance Program (LIHEAP).

We fully support the Administration's fiscal year 2000 budget request of $1.1 billion for LIHEAP. APPA also supports the request for $300 million in emergency funds in fiscal year 2000 and $1.1 billion in advanced funding for fiscal year 2001. Because the majority of LIHEAP monies are needed during a short period of time in the winter months, advanced funding for LIHEAP is critical in enabling states to effectively plan for and administer the program.

Funding cuts since LIHEAP's reauthorization in fiscal year 1995 have forced a tightening of eligibility standards and, in some cases, significant reductions in benefit levels. According to the National Energy Assistance Directors' Association (NEADA), the primary educational and policy organization for state LIHEAP directors, the number of recipients has been cut by over one million households during the recent past and average benefits have declined by about 10 percent. Prior to the dramatic reduction in LIHEAP funding in fiscal year 1995, the program was serving 20 percent of the eligible population, with one-half of the recipients being elderly or disabled Americans living on fixed incomes. Without the assistance provided by LIHEAP, many would be forced to choose between paying their home energy bill or purchasing other necessities of life, such as food.

As the debate over restructuring of the electric utility industry and the issue of providing and funding "public benefits" programs continues, some in Congress have stated their belief that electric utilities should assume the entire burden of energy assistance for low income customers as a cost of doing business. As these restructuring efforts take place at both the federal and state levels, the risks become greater that bills for residential customers, especially those with low incomes, will increase as retail markets are opened to competition. The need for full funding of LIHEAP remains critical in ensuring that all those in need of energy assistance receive help. APPA believes that any public benefits programs should not replace or supersede existing programs, such as LIHEAP, that are funded by federal appropriations.

As evidence of their commitment to low income assistance, public power systems across the country support a variety of programs providing help to low and fixed income customers. A survey conducted by the National Fuel Funds Network (NFFN) shows that publicly-owned utilities raised 14 to 26 cents more per customer than other utilities in their efforts to assist low income and needy customers in paying their bills. Many public power systems provide special rates for low income households and some have residential conservation and demand side management programs designed to reduce energy consumption.

In addition, the impact of welfare reform on energy assistance is just beginning to be felt and LIHEAP is likely to play an important role in the transition. Persons leaving the public assistance rolls are entering lower paying jobs and continue to be confronted with large energy bills. These families remain at risk.

LIHEAP is one of the outstanding examples of a successful state-operated program. The requirements imposed by the federal government are minimal and most important decisions are left to grantees.

APPA urges this Subcommittee's favorable consideration of the Administration's fiscal year 2000 budget request for LIHEAP. Again, thank you for this opportunity to present our views.

Prepared Statement of Steven R. Berg, Director of Programs, National Alliance to End Homelessness

It should be considered intolerable that homelessness continues to exist in the United States. Twelve years ago, when President Reagan signed the Stewart B. McKinney Homeless Assistance Act, many feared that homelessness was a problem too complex to solve. Since then, however, due to incredible efforts by leaders in all sectors of society (including members of both parties in Congress), we know more about homelessness than we imagined possible; we have models for effective programs for rehousing homeless people with every class of problem; we have people in the field with the know-how and energy to put these solutions into practice.

What we are missing are the resources to bring these solutions to scale. This is particularly the case in a small number of areas where real holes exist in the system of services that are necessary to permanently rehouse homeless people.

HOMELESSNESS IN 1999

Local and regional reports indicate that a surge in homelessness of emergency proportions is occurring around the country. In Maine, homelessness is up 33 percent with demand exceeding capacity for the first time in a decade. San Diego has seen families sleeping in shelter lobbies, with three times as many families needing shelter in 1998 than in 1997. In Milwaukee, single women, many with severe problems of substance abuse, have overwhelmed the capacity of the shelter system the past two winters. In South Jersey, funds for services to homeless people ran dry after three quarters of 1998. In Massachusetts, at the end of March when shelters should be clearing out, there was not an empty family shelter bed to be found anywhere in the Commonwealth. Last December the U.S. Conference of Mayors, in its annual survey of hunger and homelessness, reported another year of increasing demand for homeless shelter space.

Severe increases in homelessness should come as no surprise. A perverse effect of the good economy has been skyrocketing rents in most major cities, making housing less affordable for those who either can not work because of a disability, or who experience barriers to good employment, limiting them to low-paying jobs. These effects combine with continued long-term trends that have been pushing up homelessness since the early 1980s:

—Real wages for the lowest-paid workers have remained well below 1970s levels.

—Public assistance has become less available. State afterstate has eliminated "general relief" programs for childless adults. Many people with disabilities related to substance abuse have been dropped from the SSI program. States' TANF programs have terminated benefits to many families, and prevented others from applying. Census data indicates that there were 400,000 more children living in families with incomes less than one half the poverty level in 1997 than in 1995. All of the growth in children in extreme poverty came from families headed by women with who were working some of the time. Over 40 percent of homeless families receive no TANF benefits, even before time limits take effect.

—States have continued to reduce the number of inpatient beds for people with mental disabilities.

One of the most important findings of recent research is the existence of a relatively small number of chronically homeless, chronically ill people, making up perhaps ten percent of those who are homeless on any given night. Members of this group experience severe barriers to rehousing, with high rates of mental illness, addiction and physical health problem. They are homeless from year to year, essentially living in shelters designed for emergency use, when not living on the streets. This group takes up a disproportionate share of the resources of the emergency shelter system, as well as costing other systems (emergency rooms, jails, detoxification centers) large amounts of money because their circumstances keep them in a perpetual state of personal crisis. Those who seek to end homelessness must focus on moving this particular group into permanent, stable housing, with the supports they need to remain stable.

KNOWN SOLUTIONS

The crisis of homelessness is particularly disturbing, because we know the solutions. Much of this knowledge comes from programs funded and carried out by the federal government. We know that 80 percent of Americans who become homeless manage to leave homelessness behind in short order and never return. For the remainder, we know we need to concentrate on permanent housing that is affordable, on improving incomes to make it easier to provide affordable housing, and on providing services to help people overcome barriers to work and to housing stability. These elements need to be closely coordinated. We have been successful in all these endeavors, but the scale of the problem still threatens to overwhelm those who are battling against it.

Recent changes in federal law place more importance on the agencies funded by this subcommittee. Over the past decade, most have thought of the Department of Housing and Urban Development as the primary actor in the struggle against homelessness. Indeed, because of the difficulty in accessing many other agencies' programs, local providers have turned more and more to HUD, not only for funding for housing and shelter, but also for employment programs, substance abuse treatment, mental health services, case management, transportation and child care. Last year, however, both authorizers and appropriators made clear that they wanted HUD to focus more on much-needed permanent housing and less on matters outside HUD's areas of primary expertise. Last year's HUD appropriation required that at least 30 percent of the funding in its homeless programs go for permanent housing. The im-

pact of the shift in HUD funding away from services has already been felt in many areas. Along with increases in need, the refocusing of HUD priorities in its homelessness programs on permanent housing will put more pressure on programs funded by HHS, DoL and DoE.

PRIORITIES FOR FUNDING

With these background matters in mind, the National Alliance to End Homelessness would ask the subcommittee to pay particular attention to the following programs as it prepares an appropriation bill for the 2000 fiscal year. We also respectfully direct the subcommittee's attention to the "Statement on fiscal year 2000 Appropriations for Homeless Programs within the U.S. Departments of Health and Human Services, Education, and Labor," previously filed with the subcommittee jointly by the six national organizations that include work on federal homelessness policy as a primary part of their respective missions.

Department of Health and Human Services

Targeted homeless substance abuse program.—There is currently no funded federal program focusing on the treatment needs of homeless people with addictions. This is true despite the fact that rates of addictions are especially high among the small percentage of homeless people who can be characterized as chronically homeless, who take up a disproportionate share of shelter resources, who no doubt do the most to fuel public discontent about homeless people, and who are at the center of many local conflicts about proper responses to homelessness. Treatment works for these individuals; and yet treatment is largely unavailable. The ill effects on individuals and on communities are many. One can be seen in San Francisco, where at least 86 of the 157 deaths of homeless people on the streets last year (an all-time high) were caused by untreated substance abuse problems.

The SAMHSA reauthorization bill, now being considered in the Senate, may address this problem by including a program targeted to the addiction treatment needs of homeless people. Funding will be needed to get that program off the ground. In the mean time, SAMHSA has current statutory authority to at least fund temporary projects to apply the results of previous demonstrations, showing effective strategies for treating addictions of homeless people. The subcommittee could begin to fill a gaping hole in the system to address homelessness, by making a significant appropriation of new money to the Center for Substance Abuse Treatment, in either a program included in the reauthorization bill or in the existing "Knowledge Development and Application" line, directing CSAT to use the money for competitive grants to local nonprofit organizations to provide programs that implement research findings on the most effective means to address the substance abuse treatment needs of homeless people. The programs should provide effective services including but not limited to outreach, case management and treatment. They should work to improve the ability of "mainstream" treatment programs (those not specifically targeted to homeless people) to be responsive to the particular needs of those who are homeless. They should prioritize individuals for whom homelessness is a chronic condition. Finally, they should be closely coordinated at the local level with agencies that provide permanent housing, shelter, employment support, mental health treatment and other services to homeless people, in order to focus resources on the priority of rehousing homeless people with the most severe substance abuse problems.

The PATH program.—Another extremely difficult aspect of homelessness is the subject of the PATH program (Projects for Assistance in Transition from Homelessness), administered by the Substance Abuse and Mental Health Services Administration within HHS. PATH provides formula grants to each state for community-based outreach, case management and treatment for homeless people with severe mental illnesses, including those with a dual diagnosis of mental illness and drug or alcohol addiction. PATH grantees often search out homeless people in streets and abandoned buildings, and respond to calls from concerned business owners and others about homeless people with obvious mental illnesses who have no connection to local networks of services.

In fiscal year 1996, when PATH funding was cut to $20 million, its grantees served 76,000 people, approximately $263 per person per year. This is in sharp contrast to the cost of involuntary hospitalization in a psychiatric facility, often hundreds of dollars per day.

Although PATH is extremely effective, its resources are overextended. Those with mental illnesses constitute up to one-third of homeless adults at any point in time, and again, the rate is almost certainly higher for those who are chronically homeless. Homeless service providers often identify specialized mental health outreach and treatment as a service that is in too-short supply. PATH's fiscal year 1999 appropriation is $26 million, still well below its $33.1 million appropriation for fiscal

year 1991. Even at its high point in 1994, PATH served 127,000 people. The most recent available count of homeless people with disabilities, from 1987, showed despite the most conservative possible assumptions that even that long ago there were at least 180,000 adults with severe mental illnesses who were homeless at any given time. The actual number by now is almost certainly higher.

Because homeless people with severe mental disabilities are so difficult to move into permanent housing, and because the PATH program has worked so well, the National Alliance to End Homelessness believes that a major increase in PATH funding is necessary in order to complement HUD and other homeless programs and ensure that the drive to move homeless people into permanent housing includes those with mental illnesses. The Alliance joins with other national homelessness organizations to recommend an appropriation of $40 million for fiscal year 1999.

Runaway and Homeless Youth Programs.—This term encompasses three separate line items within the Administration for Children and Families: Children and Family Services Program/Runaway and Homeless Youth; Children and Family Services Program/Runaway Youth—Transitional Living; Violent Crime Reduction Programs/Runaway Youth Prevention. These programs focus on young people who are homeless, literally rescuing them from the most dangerous kinds of situations, sheltering them and giving them the skills they need to live safely and independently in permanent housing.

Health Care for the Homeless.—This is one of the components of the Community Health Centers line within HRSA. It funds local clinics that cater to the unique needs of homeless people for primary health care. The Community Health Centers are the major federal response to the growing number of uninsured adults who do not qualify for any individual entitlement program.

Department of Labor

Homeless Veterans' Reintegration Project.—This is an extremely cost-effective program aimed at reintegrating homeless veterans into the community through the workplace. While it is a small program, it leverages other resources from the Department of Veterans Affairs and elsewhere. The Alliance, along with other homelessness organizations, recommends full funding of $10 million for this program.

Department of Education

Education for Homeless Children and Youth.—When families become homeless, school can serve as a place of stability for children the rest of whose entire existence is disrupted. This program provides funding to states and some localities to ensure that school access for homeless children is a reality. The McKinney Act included a requirement that all school districts ensure that homeless children are able to attend school, but this requirement can be hollow without accompanying funding. Due largely to this program, school attendance by homeless children has risen from 50 percent in the mid-1980s to 86 percent in the mid-1990s. This is a stunning success, but work remains to be done.

CONCLUSION

Local homeless service providers have the know-how and energy to build coordinated systems to permanently rehouse homeless people. Recently they have had to scramble to keep up with unacceptable numbers of Americans becoming homeless every day. They need tools—effective programs to give homeless people the treatment and services they need to get themselves rehoused and reconnected to their communities.

PREPARED STATEMENT OF THE AMERICAN GAS ASSOCIATION

The American Gas Association (A.G.A.) represents 189 local natural gas utilities that deliver gas to almost 60 million homes and businesses in all 50 states. Additionally, A.G.A.'s members deliver the natural gas to more than 50 percent of the low-income households in this country. We are pleased to have an opportunity to submit testimony to the Subcommittee in support of federal funding for the Low-Income Home Energy Assistance Program (LIHEAP).

First and foremost, we would like to thank this subcommittee and the Congress for ultimately approving a fiscal year 1999 appropriation of $1.4 billion for LIHEAP, which includes $300 million in emergency assistance. This appropriation is significant because it reverses a serious downward trend in LIHEAP appropriations from $2.1 billion in fiscal year 1985 to $1.2 billion in fiscal year 1995. In addition, we appreciate that the Congress approved a similar advance appropriation for fiscal year 2000.

We are requesting the subcommittee to appropriate a minimum of $1.4 billion for LIHEAP in fiscal year 2000. Further, we urge the subcommittee to also adopt a modest goal of providing sufficient LIHEAP funding to renew assistance for the more than 1 million households that were eliminated as a result of federal budget cuts beginning in fiscal year 1995. To achieve this goal, we urge the subcommittee to provide an advance fiscal year 2001 appropriation of $1.6 billion for LIHEAP.

We would like to take this opportunity to demonstrate that the basic need for LIHEAP funding continues. The need is constant on an annual basis, particularly during the extreme cold and hot weather months. In addition, we would like to discuss two important trends that will have an impact on low and fixed income energy consumers: welfare reform and energy restructuring.

THE NEED FOR LIHEAP CONTINUES

According to the U.S. Department of Health and Human Services:

—Federal budget cuts to LIHEAP have reduced the number of households served from 6.0 million during fiscal year 1994 to 4.6 million today, a reduction of over 1 million households served.

—Federal budget cuts to LIHEAP have also reduced by 10 percent the amount of aid provided to those who continue to receive assistance.

—LIHEAP currently assists only 19 percent of the 29 million households eligible for such assistance.

—Low and fixed income households currently spend 18.5 percent of their annual household income on energy and the proportion has not changed considerably since LIHEAP was initiated. This is nearly three times higher than the 6.7 percent spent by the average U.S. household.

—Nearly 70 percent of the families receiving LIHEAP assistance last year survived on an annual income of less than $8,000—this figure has not changed in years and does not take into account inflation.

—In 1995, nearly 34 percent of the households receiving assistance with heating costs had at least one member of 60 years or older.

Finally, delivered energy prices today are higher than they were during the energy crisis of the late–1970s early–1980s. Since Congress passed LIHEAP in 1981, the weighted average price of energy for heating homes has increased 53 percent, indicating that home heating assistance funds are needed more now than when the program started.

The facts above demonstrate that the need for LIHEAP assistance is as great as ever. We urge the subcommittee to appropriate a minimum of $1.4 billion for LIHEAP in fiscal year 2000 and an advance fiscal year 2001 appropriation of $1.6 billion.

PRIVATE SECTOR ASSISTANCE IS STRETCHED TO THE LIMIT

Over the years, many private sector energy assistance programs have been created to supplement the basic LIHEAP program. For example, most local gas utilities have programs and policies that enable low-income customers to manage their gas bills—such as deferred and budget payment plans, payment counseling, weatherization programs, fuel funds, subsidized rates, and matching grants. LIHEAP has also received support from a variety of community-based social service organizations such as Catholic Charities, the Salvation Army, the National Fuel Fund Network and churches and synagogues. While states, local governments, and the private sector have demonstrated their capacity to develop creative and effective programs to address some energy assistance needs, collectively these programs serve only as a supplement, not a replacement for federal LIHEAP funding.

Even a decade ago, LIHEAP assistance was barely sufficient in supplementing a low income family's ability to maintain heating service through an entire winter. Today, LIHEAP has been reduced to half of that level. As a result, state and local fuel assistance directors are stretched to the limit. According to the Colorado Energy Assistance Foundation, the inability to pay utilities is second only to the inability to pay rent as a reason for homelessness. In Charlotte, North Carolina, a relatively prosperous community, the local fuel fund has reported a 20 percent increase in demand for LIHEAP funding. Private sector and charitable efforts to supplement federal LIHEAP funding simply cannot meet the demand without an increase in federal LIHEAP program funding.

TRENDS: WELFARE REFORM AND ENERGY RESTRUCTURING

In addition to the basic need for LIHEAP assistance, there are two very real social and market trends that will have a substantial impact on low-income energy consumers—welfare reform and energy restructuring. As this subcommittee considers

the LIHEAP budget, it must recognize these trends and account for the impact they will have on low-income energy consumers. In fact, welfare reform and energy restructuring make it more important than ever to have a healthy LIHEAP program.

Welfare reform, of course, was passed in 1996. LIHEAP is consistent with welfare reform. LIHEAP is a block grant program that provides the states maximum flexibility. LIHEAP's administrative costs are capped at ten percent. More than ninety cents of every dollar goes to helping people stay warm, cool, or making their homes more energy efficient through weatherization. LIHEAP's success results from minimal federal requirements and discretion for the states in deciding important issues of eligibility, benefits and program management. Its efficiency and effectiveness are second to none.

More importantly, however, is the impact welfare reform is having on LIHEAP. As individuals move off the welfare rolls and into the workforce, most individuals will enter low paying positions, earning minimum wage or slightly above. According to the U.S. Conference of Mayors, "city officials report that the strong economy has had very little positive impact on hunger and homelessness. Low paying jobs that cannot support a household continues to be a very troublesome problem." As a result, many of these individuals are still confronted with energy bills that they cannot pay. LIHEAP serves as a bridge to help people move off the welfare rolls, into the workplace, and still maintain self-sufficiency.

Take for example, the Community Action Agency (CAA) in New Haven Connecticut which has reported that while the number of LIHEAP applicants are about average this year, the money may not be sufficient due to an increase in poverty. New Haven CAA executive director Marcial Cuevas stated, "What we see is more requests for additional assistance after they've exhausted what they already received. If this program (LIHEAP) did not exist, many people would go cold."

Clearly, the transition from welfare to work has put additional pressure on LIHEAP. If federal LIHEAP funding is reduced further, many hard working, low income families will have no where to turn. In fact, the very success of welfare reform during this transition period may well depend on LIHEAP.

Another important trend is energy restructuring. The states and Congress are considering utility restructuring measures which will begin to change the way in which consumers purchase energy for their homes. Residential energy choice programs will allow customers to buy electricity or natural gas from a non-utility supplier, much as they select a long distance telephone carrier.

There are two important considerations concerning the impact energy restructuring will have on low-income consumers. First, under the current regulatory scheme, local gas utilities have an obligation to serve all customers regardless of their ability to pay. In an open, competitive energy marketplace, the continued obligation to serve all customers threatens a local gas utility's ability to remain competitive. As a result, local gas utilities may not be able to maintain or subsidize programs such as LIHEAP. If not, there will be an increasing demand on federal funding.

The second consideration concerns the cost of energy to residential consumers. According to a recent study published by Oak Ridge National Laboratory for the Department of Energy, electricity restructuring may lead to the break up of the traditional utilities into generation, transmission, and distribution components. If this occurs, fixed monthly charges may rise to more appropriately reflect the fixed portion of distribution utilities' costs, and thus come to comprise a larger share of a customer's monthly bill. Although, "restructuring proposals intend to make electricity more affordable for society through the competitive pricing of generation services, competitively priced generation does not ensure lower prices for low-income customers." [1] Clearly, restructuring does not replace the need for LIHEAP.

Finally, cutbacks in federal LIHEAP funding have forced some states to search for supplemental LIHEAP funding. Some states have used energy restructuring as a source for supplemental LIHEAP funding through wire charges and other mechanisms. These funds, however, merely serve as a supplement, and do not serve as a replacement to federal LIHEAP funding. In fact, federal support for LIHEAP is more important than ever in an uncertain energy marketplace.

CONCLUSION

In conclusion, the need for LIHEAP assistance is much greater than the coverage provided by federal funds. Over 1 million households have already been removed from the program due to recent federal budget cuts. The need for LIHEAP will only

[1] Oak Ridge National Laboratory, "Low-Income Energy Policy in a Restructuring Electricity Industry: An Assessment of Federal Options", July 1997, p. 15.

increase as welfare reform and energy restructuring continue to evolve. Thus, the A.G.A. urges the subcommittee to approve a minimum of $1.4 billion for LIHEAP in fiscal year 2000 and a $1.6 billion advance appropriation for fiscal year 2001. Thank you for the opportunity to testify.

PREPARED STATEMENT OF PATRICIA E. MARKEY, LEGISLATIVE CONSULTANT, UNITED DISTRIBUTION COMPANIES

Mr. Chairman and members of the Subcommittee: United Distribution Companies (UDC) is a group of companies providing natural gas distribution service to customers chiefly in the Midwest and Northeast. Nearly half of all LIHEAP-recipient households heat with natural gas. UDC companies are deeply committed to meeting the energy needs of all our customers, in particular, those of low and fixed-income. Our member companies are a vital part of the communities we serve.

Mr. Chairman, most regions of the country experience cold weather—sometimes record-cold. In particular, some Northeastern and Midwestern areas regularly suffer through brutal weather well below zero for extended periods of time. In one recent winter, as the weather began to turn bitter, prices for fuel oil, propane gas, and in some states natural gas rose dramatically over previous levels. Oil prices skyrocketed and propane prices doubled and tripled in some areas of the country.

Last summer, a brutal heat wave struck eleven southern and southwestern states (three represented on your subcommittee). Tragically, the scorching heat wave killed over 100 Americans. LIHEAP monies were released to help vulnerable low-income households pay their home energy bills and avoid life-threatening situations.

These conditions challenged and stressed the "average" American household, but to millions of low-income elderly, disabled and working poor families this confluence of factors became overwhelming. The choices many were forced to make were untenable; however, the situation that many low-income families face in trying to meet their home energy needs is difficult even under "normal" circumstances. Most of us can take the comfort of a warm home during the winter, or some means of cooling in the heat of summer for granted. Try to imagine what it would be like if you did not have the resources to secure these basic necessities. For millions of seniors, disabled, working-poor families, and others across this country, LIHEAP is more than economic assistance, it is a lifeline for health and safety. No one can go without heat in the winter.

Mr. Chairman, in the coming months you and your colleagues will work to craft necessary spending measures for fiscal year 2000 that will set the fiscal spending priorities for the next year. As you chart the course to continue to protect our nation's fundamental health, education and social services priorities, we ask you to provide critical funding for home energy assistance for low-income Americans.

LIHEAP FUNDING RECOMMENDATION

Mr. Chairman, we applaud you, Senator Harkin and other members of this subcommittee for your tireless efforts last year to fashion a broad bipartisan Labor-HHS-Education spending bill under the current spending restraints. We also commend you for your leadership in restoring necessary funding for energy assistance. This year, on behalf of all of our residential customers—especially the low-income customers who live in our communities—We urge you to continue on this course and to restore critical funding for LIHEAP. We ask for your support for the Low Income Home Energy Assistance Program, and urge that this Subcommittee and the Congress adopt the following in the fiscal year 2000 Labor, HHS and Education Appropriations Bill:

1. Provide an appropriation of at least $1.319 billion for the fiscal year 2000 LIHEAP;

2. Provide an "advance appropriation" of at least $1.319 billion for the fiscal year 2001 LIHEAP; and

3. Limit the set-aside for the Leveraging Incentive Program.

In addition to the funding above, UDC also endorses the continuation of the "Emergency Contingency Fund," consistent with LIHEAP's authorization statute, which authorized $600 million. However, in our view, the emergency funds should not be used in lieu of regularly appropriated funds for LIHEAP. It is essential that the states have the necessary monies to assist needy households and not be subject to the vagaries of the release of emergency monies.

After a careful review of the facts, UDC is urging a restoration of LIHEAP core funding to at least the $1.319 billion level. In recent years, funding for the program has dropped precipitously. The National Energy Assistance Directors' Association (NEADA) estimated that between fiscal year 1995 and fiscal year 1997, 1.3 million

needy households—many of them elderly or disabled—lost necessary aid due to insufficient funds. We believe that the $1.319 billion in regular appropriations is the bare minimum amount necessary to enable the restoration of crucial aid to those households that lost LIHEAP assistance over the past several years.

The U.S. Department of Health and Human Services reports that between fiscal year 1981 and fiscal year 1995, the number of federally-eligible households has risen 45 percent; during this same time, however, LIHEAP funding was cut from $1.85 billion to $1.419 billion. The fiscal year 1999 funding for the program is even lower—$1.1 billion. In turn, the number of households assisted dropped dramatically. In 1981, over 7 million eligible households received LIHEAP aid; however, last year only 4.5 million needy households were assisted with LIHEAP benefits. Reduced federal funding has also resulted in smaller assistance grants for those in need of LIHEAP.

We applaud the Congress for recognizing the pivotal role that advance appropriations plays in the implementation of LIHEAP by the states, and we urge you to continue to give the states the necessary tools to plan the next year's program prior to the next heating season. In the past, piecemeal funding had a disruptive effect on the states' abilities to plan and implement their LIHEAP Programs. An advance appropriation of at least $1.319 billion for fiscal year 2000 is central to the effective administration of the program.

UDC shares the views expressed at the LIHEAP reauthorization hearings in April 1997 before the House Subcommittee on Early Childhood, Youth and Families. Witnesses questioned the value of the Leveraging Incentive Program given the inadequacy of funding. Unfortunately, LIHEAP has not been funded at the levels the Congress intended when the Leveraging Program was designed.

Congress ought not to penalize low-income seniors and families living in states that do not mandate programs for low-income households, or do not have casino revenues for lifeline programs dedicated to vulnerable citizens. There is no "level playing field" in the states when it comes to leveraging. Also, recent changes in the federal rules on leveraging marginalize the benefit of states' leveraging efforts. The paperwork burden on the states for qualifying for leveraging is disproportionate to the size of the program. We question the value of continuing the effort at LIHEAP's current funding. Such constraints also make the Residential Energy Assistance Challenge (R.E.A.Ch.) Program unrealistic. In addition, R.E.A.Ch. is duplicative of other ongoing efforts.

BROAD SUPPORT FOR LIHEAP

Members of the Subcommittee must recall the formidable efforts of your colleagues to restore critical funding for LIHEAP during the 105th Congress. Mr. Chairman, we are sure that you are also aware of current congressional letters—with broad bi-partisan support—urging the restoration of LIHEAP in the fiscal year 2000 Budget.

In addition, the National Governors' Association (NGA) supports maintaining adequate federal funding for LIHEAP. The NGA has endorsed LIHEAP as a targeted block grant that provides the states with the necessary flexibility to best assist the elderly, disabled, and working-poor households in meeting their home energy needs. The Governors have also urged the Congress to continue to provide advance appropriations for LIHEAP to avoid unnecessary disruption in the program.

Another organization supporting LIHEAP, the National Association of Regulatory Utility Commissioners (NARUC)—representing the state regulatory bodies responsible for regulating the rates and services of electric and gas utilities throughout the United States—has also had a long-standing policy urging the Congress to reject any further cuts or rescissions to LIHEAP. In its most recent action taken on a resolution adopted in February, NARUC has urged the Congress to provide at least $1.3 billion for fiscal year 2000 and advanced funding of at least $1.3 billion for fiscal year 2001, and urged the continuation of advance appropriations. LIHEAP is recognized as the foundation for many low-income programs authorized/mandated by the state public utility commissions.

THE NEED: LIHEAP HELPS SENIORS AND THE DISABLED

Let us examine the households that actually receive LIHEAP. Of the 5.5 million households which received LIHEAP assistance in fiscal year 1995 [The Department of Health and Human Services is now in the process of updating this data.], approximately 70 percent of these families had annual incomes of less than $8,000. In fact, in Pennsylvania and Iowa, 61 and 87 percent respectively, of LIHEAP recipients earned less than $8,000. Yet despite this low income, the majority of recipi-

ent households are not receiving public assistance. As an example, in Illinois, 70 percent of LIHEAP-recipient households are not on welfare.

On average, one-third of LIHEAP households are elderly. States, such as Maine, South Dakota, Georgia, Tennessee, South Carolina, Nevada, and Louisiana, and Arkansas find more than 40 percent of their LIHEAP recipient households include an elderly person. Four states represented on your subcommittee, Mississippi, Texas, South Carolina, and Nevada had approximately 60 percent of recipient households which included an elderly person(s). Due to federal cuts, many of these households may have lost assistance. For example, in Pennsylvania, 25 percent of seniors that received LIHEAP in fiscal year 1995 lost all benefits in fiscal year 1997 due to cuts. Finally, nationwide, nearly one-quarter of the households served include a disabled member. The following states had in excess of 30 percent of LIHEAP-recipient households with a disabled member: Mississippi, New Hampshire, Idaho, Texas, Arizona, South Carolina, Nevada, Wisconsin, Georgia, Oregon, North Carolina, Tennessee, Arkansas, Kentucky, Louisiana, California, and Illinois.

According to a 1994 report by Oak Ridge National Laboratory, many low-income households' expenditure for residential energy (their energy burden) exceeds 30 percent of income. The report also states that all the low-income households which are federally eligible for LIHEAP spend over $1,000 per year or 10 percent of income on energy. Typically, low-income households pay four times the percentage of monthly income for energy costs than an average household in America pays.

Assistance critical to poor making transition out of welfare/working poor

A key underlying principle of Welfare Reform is to assist low-income families and individuals become/remain self-sufficient. LIHEAP is such a program; LIHEAP is the antithesis of welfare. LIHEAP is designed to address the needs of low-income families in meeting their annual energy expenses. LIHEAP promotes self-sufficiency; it protects these families on the edge of poverty from falling deeper into debt, and allows them to have more control over their lives and their resources. LIHEAP will become all the more important as more welfare recipients make the transition to employment.

Working-poor households account for approximately one-third of the LIHEAP-recipient population. Changing dynamics in the work place, including inadequate and stagnating wages, part-time employment, and fewer benefits are swelling the ranks of the working poor. Some of these households have learned that a job does not necessarily get you out of poverty. To illustrate, last year, Catholic Charities USA released the results of its annual survey—the most comprehensive report available of private social services and activities. It reported that increasingly, working people are coming to them in crisis. This organization provided emergency food and shelter to almost 7.9 million people in 1996. Over half of those assisted were not on welfare. They need help with grocery or utility bills to make it to the next paycheck. For many, the choices are between heat and food, rent, medicine for a child, or bus fare to work. Catholic Charities has cited that there are not enough "decent" jobs; therefore, many people will not have "the safety net of minimum benefits, and our agencies simply do not have the resources to handle the increased demand." Thus, everyone has not benefited from the economic expansion.

Low-income families struggle to stay together. With resources stretched thin, a meaningful LIHEAP benefit helps families face daily challenges to pay for basic necessities. If you take away or reduce their energy assistance, that is one more push toward dependence. These families are worth the investment of a LIHEAP benefit to keep them independent. LIHEAP fosters independence rather than dependence. It helps low-income people stay off welfare.

HEALTH AND SAFETY CONCERNS

In attempting to argue that LIHEAP is no longer needed, program critics have misrepresented "shut-off" moratoria as a "safety-net" in protecting low-income families. In those states in which moratoria exist, the moratoria may provide some protection for low-income consumers, but no long-term protection. Moreover, moratoria do not exist in all states (including cold weather states). In fact, the NARUC survey on "uncollectibles" catalogues the states policies on "shut-offs," and illustrates that the states' policies vary greatly. In addition, moratoria do not govern unregulated fuels—such as propane, fuel oil, or wood; often do not govern emergency situations; and do not relieve low-income families of the ultimate obligation to pay for their home energy costs when the moratoria end. In addition, HHS reports that nearly one-third of LIHEAP-recipient households use bulk fuels; thus, are unprotected. In states such as Wisconsin, Minnesota and New Hampshire between 30 to 40 percent of their low-income households use unregulated fuels.

With higher payments for home heating fuel, low-income families face tough choices: heat-or-eat; go further into debt which will jeopardize their ability in the future to become self-sufficient; or use potentially unsafe alternative methods to heat which could result in tragedies. Elderly households might use single room space heaters and turn their thermostats down; these actions will increase the risk of hypothermia for these customers. Yet other low-income customers will move households together to make ends meet. Tragically, overcrowded substandard housing, and the improper use of space heaters have proven to have disastrous consequences in our communities.

TARGETED LIHEAP BLOCK GRANT WORKS

Mr. Chairman, LIHEAP works! As designed by the Congress, LIHEAP is a block grant that is targeted to assist low-income households with the costs of home energy. While there are broad federal guidelines for LIHEAP, the states are encouraged to tailor their programs to best meet their individual needs. The Governors determined what agencies should administer the program, what eligibility standards will be used, how benefits will be structured, the guidelines for the crisis program, and the range of assistance to be rendered.

In addition to program flexibility, the administrative costs of the program are minimal—in the range of seven to eight percent. This ensures that the majority of LIHEAP dollars (generally 92 to 93 percent) are directed to energy assistance benefits for the low-income families that it was intended to help. Carry-over funds are minimal and typically run about 3 percent in most years. Late funding decisions by the Congress have unfortunately forced some states to further restrict eligibility and to reserve additional start-up funding for September.

LIHEAP IS THE CENTERPIECE OF PRIVATE AND UTILITY EFFORTS

The burden of low-income household needs does not rest solely on the Federal Government. Our member companies are involved in and concerned about the well-being of our communities—both in economic and human terms. The states and the private sector recognize their responsibility to contribute to the needs of these consumers.

UDC member companies have developed a host of innovative and effective programs to assist their low-income consumers; these include: operating and/or contributing to fuel funds; providing discounts and credits to low-income customers; providing partial or full waivers of home energy connection and reconnection fees, and late payment charges; partial or full waiver of home energy security deposits; and partial forgiveness of home energy arrears. Moreover, many of our companies are involved in various energy conservation/management activities. Overall, millions of dollars each year are dedicated to assisting the low income with their fuel bills. However, these efforts and most other private efforts are built around LIHEAP as their cornerstone.

Private charitable efforts alone cannot "take up the slack" for reduced federal funding. Last year, Caroline Myers, Executive Director of the Crisis Assistance Ministry in Charlotte, North Carolina, testified on this subject before the House Labor, HHS, and Education Appropriations Subcommittee on behalf of an organization which she chairs, the National Fuel Funds Network (NFFN). NFFN's member fuel funds are organizations that raise private contributions in their local communities to help low-income households pay their home energy bills. Fuel funds range from small church groups which distribute hundreds of dollars in a single neighborhood to large independent organizations which distribute millions of dollars across a state. Fuel funds may be a division of a large, social service agency or they may be operated by a local utility or energy company. NFFN's testimony provided greater detail about other private sector programs that exist to help bridge the gap between federal LIHEAP funding and the need that exists throughout the nation. More recently, a representative from the National Headquarters of the Salvation Army, the biggest private administrator of Fuel Fund Assistance, sent a letter to the House Labor-HHS-Education Appropriations Subcommittee underscoring the importance of funding LIHEAP at $1.3 billion, at the minimum, citing that private efforts cannot make up for adequate LIHEAP funding.

CHANGING ENERGY POLICIES & UTILITY RESTRUCTURING CREATE UNCERTAINTY

More than 50 percent of low-income households in this country heat their homes with natural gas. Federal and state policies favoring greater competition in both the electric and natural gas industries have shifted significant costs away from industrial customers, and other users with energy alternatives, to residential customers. These households are now paying a higher share of the costs of purchasing and

transporting natural gas today than they did in 1980, when LIHEAP was first created. Thus, low-income households continue to face increasing energy burdens.

During the LIHEAP reauthorization hearings held by the House Subcommittee on Early Childhood, Youth and Families in the last Congress, Joel Eisenberg, Senior Analyst for Public Policy at Oak Ridge testified on the potential impact of the restructuring of the electric industry on low-income households. He stated that there is "substantial uncertainty as to whether residential consumers in general, and low-income consumers in particular, will benefit from these changes to a significant degree. In some places there is concern that residential rates may actually increase." Eisenberg noted that momentous change in the electric and gas industry is in process. He cited recent data for the natural gas industry from the Energy Information Agency (EIA) which indicate that between 1985 and 1995, savings for residential consumers have been relatively small so far—in the range of 1 percent.

Deregulation and increasing competition create intense financial pressures on gas and electric utilities. As a result, these companies cannot afford to shoulder the responsibility associated with serving low-income households without government support in the form of continued LIHEAP funding. Since its inception, LIHEAP has been a strong and successful public-private partnership that has worked to address the problem. If government pulls out of this partnership, a serious financial hardship will be created for our low-income citizens.

CONCLUSION

Mr. Chairman, the reauthorization hearings examined the LIHEAP Program. Witnesses included Members of Congress, as well as representatives from the states, and the private and public sectors. The panel included a representative from a local agency and a former LIHEAP-recipient.

Mr. Specter, the witness gave a strong endorsement of LIHEAP and the need for more adequate funding. They told compelling stories about low-income households who have benefited from the program. The Maryland LIHEAP-recipient described her situation as the primary wage earner for a family of five. Behind in her utility payments, this divorced mother was scheduled to be disconnected. Qualifying for LIHEAP was the linchpin to securing continued utility service and working out a long-term repayment schedule.

The witness representing a local agency recounted information about numerous beneficiaries of the program, including a divorced mother in her thirties with three young children. Recently diagnosed with cancer, this mother had to quit her job in January when she developed side effects to the chemotherapy. This forced her to go onto AFDC and file for disability. Her income dropped from $1,600 to $406 per month; consequently, she fell behind in her utility bills. LIHEAP helped bridge the gap during this crisis. As the House witness cited, "This is an example of the kind of situation that can plunge a self-sufficient working family into poverty."

Mr. Chairman, the changes in the welfare system are already causing profound implications. As families move from dependence towards independence, they will need targeted supplemental assistance. Families in transition normally start at, or near, minimum wage levels. In order for them to continue working and gaining employment experience, so that they can be eligible for better jobs in the future, they need help to maintain a basic standard of living from programs such as LIHEAP.

As the winter ends, problems for the poor do not! The spring brings collections pressures on unpaid heating bills. Without the safety-net afforded through LIHEAP low-income households could lose gas and electric service. The truth is simple. LIHEAP is a public-private partnership program that works for low-income households and helps to make energy service available and more affordable to them.

DEPARTMENT OF EDUCATION

PREPARED STATEMENT OF PETER LENNIE, PH.D., DEAN FOR SCIENCE AND PROFESSOR OF NEURAL SCIENCE

I appreciate this opportunity to present testimony to the Subcommittee to discuss a scientific research project which is not only an important priority for New York University, but which we believe will advance the national interest through enhanced scientific understanding of brain development.

Our project addresses the programmatic priorities of this subcommittee, which is on record in support of "research in the area of brain development, mechanisms that underlie learning and memory, the acquisition and storage of information in the nervous system, and the neural processes underlying emotional memories as they relate to intellectual development and cognitive growth." We thank the Sub-

committee for taking the time to consider and give its support to the important research being conducted in this area—an area of great strength at New York University. We at NYU firmly believe that in the coming decades, a federal investment in mind and brain studies will repay itself many times over.

In line with the Subcommittee's interests, New York University is undertaking to establish a Center for Cognition, Learning, Emotion and Memory (CLEM). This Center will draw on the University's strengths in the fields of neural science, biology, chemistry, psychology, computer science, and linguistics to push the frontiers of our understanding of how the brain develops, functions and malfunctions. In addition, as a major training institute, the Center will help prepare the next generation of interdisciplinary brain scientists.

To establish this Center, New York University is seeking $10.5 million over five years to support and expand the research programs of existing faculty, attract additional faculty and graduate and postgraduate trainees, and provide the technical resources and personnel support that will allow us to create a premier, world class scientific enterprise. Individual researchers in the science programs at NYU compete for investigational support through traditional routes, very successfully. However, these traditional funding sources do not address the specific need for establishment of a new cross-disciplinary area of scientific study, particularly one that transcends biomedicine, psychology, education, computer science, cognitive science, and linguistics. Nor do they provide the extensive funding necessary for faculty and student support and personnel and technical resources. Support from the Subcommittee on Labor, Health and Human Services, and Education would enable us to meet these needs, and to fully develop the potential New York University has to produce a new understanding of the brain, and new ways of using that knowledge for improving the national welfare.

RESEARCH APPLICATIONS

Studies of the fundamental neurobiological mechanisms of the nervous system help educators, health care providers, policy makers, work force managers, and the general public by informing our understanding of normal brain development and function in both children and adults, thereby making it easier for us to detect and correct impediments that affect our ability to learn, think, and remember, and mature as productive members of family and society. Research in this area will ultimately contribute to a better understanding of how children learn at different stages; how educators can improve students' retention and memory; how childhood and adult learning is shaped by different cognitive styles; how aging affects memory; and how diseases alter memory. There are enormous potential applications for early childhood intervention, teacher training, educational technologies, job training and retraining, and diagnosis and treatment of mental and memory disorders.

Early Childhood and Education: Research into the learning process as it relates to attention and retention holds important implications for early childhood development. Scientific findings on brain development generated by researchers at NYU point clearly to windows of learning opportunity—that open and close—with important implications for when children best learn. Understanding how, when and under what conditions learning proceeds can lead to practical applications for parents, caregivers and educators. In the midst of a national debate on education reform, thousands of educational innovations are being considered without the advantage of a fundamental understanding of the learning process. CLEM researchers, coupled with educational psychologists and their expertise in normal childhood development, can contribute to a better understanding of how parents can foster their children's cognitive growth, how children learn at different stages and use different styles, how educators can accommodate those styles, and how educational technology can be harnessed to stimulate interest and increase retention and memory. These findings are crucial to national efforts to enhance early childhood education, and improve teaching and learning in the elementary grades. At NYU, research by cognitive and neural scientists will be enhanced by collaboration with scholars in the School of Education and the Center for Digital Multimedia; the Center brings together educators, laboratory scientists and software designers to explore how interactive multimedia technologies enhance teaching and learning.

ADVANCES IN BIOMEDICAL AND BEHAVIORAL RESEARCH

Research conducted in our Center will by its nature address the loss of memory through aging or disease, as well as disorders of emotional systems that commonly characterize psychiatric disorders. At NYU, pioneering research into the neurobiology of fear is generating important information about the brain systems that malfunction in, for example, anxiety, phobias, panic attacks, and post-trau-

matic stress disorders. The brain's fear system is involved in many human emotional disorders, and malfunctions in emotional systems commonly characterize serious psychiatric disorders. Research into the neural mechanisms of fear will help us understand the source of emotions, how they are triggered by circumstance, why these emotional conditions are so hard to control, and, of greatest practical importance, how they can incapacitate, undermine attentiveness, and weaken our capacity to learn and remember skills. Ultimately, our research will generate clues for prevention and treatment of emotional disorders, focusing perhaps on the ways in which unconscious neural circuitry can, in effect, be altered or inhibited.

Job Training and Retraining: Research into the fundamental processes of cognition and learning, emotion and memory will help address the persisting challenge the nation faces in training new recruits to the labor force, preparing welfare recipients to move into the labor force, retraining workers dislocated from downsized industries, and retraining workers in new technologies. Basic scientific research into neural and psychological mechanisms can help rationalize job training programs and increase their effectiveness.

FEASIBILITY: INSTITUTIONAL STRENGTHS

New York University is well positioned to create and operate a major multidisciplinary research and training center. There is commitment to the CLEM project at the highest level of the University administration, established frameworks for interdisciplinary collaboration, strengths in neurobiological, psychological and computational sciences, and standing in the international scientific community. The nation's largest private university, with 13 schools and over 49,000 students, NYU is a leading center of scholarship, teaching and research. It is one of 29 private institutions constituting the distinguished Association of American Universities, and is consistently among the top U.S. universities in funds received from foundations and federal sources.

As the core of a decade-long multi-million dollar science development plan, NYU created a premier neuroscience and cognitive psychology program that encompasses a pre-eminent faculty and generates substantial external funding from federal and state agencies as well as the private sector. These investigations have attracted millions of federal dollars from the NIH, the NSF and the EPA. In addition, NYU has received major funding from the most prestigious private foundations supporting the sciences. This includes the Howard Hughes Medical Institute (HHMI)—the foundation most active in support of the life sciences. (NYU is now home to no fewer than six HHMI Investigators, with corresponding funding from the Institute.) The HHMI also has awarded NYU two major grants, each exceeding $1 million, from its Undergraduate Biological Science Initiative Program, as well as a major facility improvement grant. The W. M. Keck Foundation also awarded two grants, each exceeding $1 million, for facility and program development in the neural and cognitive sciences; one grant funded the renovation of a major new laboratory in emotional memory studies. The Alfred M. Sloan Foundation similarly awarded two major grants totaling $2 million to found the Sloan Center for Theoretical Visual Neuroscience—one of five institutions chosen to implement the Foundation's national initiative in theoretical neurobiology. Neural science faculty have, as individuals, won prestigious awards, including HHMI Investigator, NSF Presidential Faculty Fellow, NIH Merit Awardee, McKnight Foundation Scholar in Neuroscience, and MacArthur "Genius" Fellow.

Neural science at NYU is particularly well known for research in the neural basis of visual processing and perception, theoretical/computational neurobiology, the linkage of sensation and perception with action, emotional memory, plasticity in the visual and auditory system, molecular and developmental neurobiology, and cognitive neuroscience. NYU scientists have made important contributions to visual processing, deriving the most successful methods available for studying nonlinear interactions in neuronal information processing; emotion, giving the first real glimpse into the neuroanatomy of fear; neural development, with landmark work on the vision system; and the neural bases for auditory function, including neural sensitivity to auditory motion stimuli.

With these strengths, NYU is particularly well placed to create a distinctive center that will capitalize on expertise in physiology, neuroanatomy, and behavioral studies and build on active studies that range from the molecular foundations of development and learning to the mental coding and representations of memory. The Center will encompass diverse research approaches, including mathematical and computational modeling, human subject psychological testing, use of experimental models, and electro-physiological, histological, and neuroanatomical techniques.

While other academic institutions are also studying the brain, NYU has special strengths in important emerging research directions. To elaborate, vision studies at NYU follow an integrated systems approach that has been shown to be highly successful approach in unraveling this complex system, and that has established NYU as an internationally known center. The interest in vision, a key input to learning, is associated with focused studies on the learning process, particularly, the interaction with memory and behavior. NYU vision scientists are studying form, color and depth perception; visual identification; the varieties of visual memory; and the relationship of vision and perception to decision and action. Studies ask: How does vision develop? How does the brain encode and analyze visual scenes? What are the neural mechanisms that lead to the visual perception of objects and patterns? How do we perceive spaces, depth, and color? How does the brain move from vision and perception to planning and action?

NYU is also at the frontier of studies in the neuroanatomy and physiology of emotion, a new area of exploration that complements studies of how perceptions, thoughts, and memories emerge from brain processes. Work recently conducted at NYU and elsewhere has established the biological basis of emotions and the patterns by which they are expressed within the neural circuits of the brain and the actions of the body. The new studies have found that there are multiple systems in the brain, each having evolved for different functional purposes, and each producing different emotions. Work being conducted at NYU also suggests that the neural circuits supporting the expression of emotions are highly conserved through evolution. They persist, unconsciously, in our daily behavior, and shape our reactions to events well before we rationally and consciously process the event. Scientists at NYU are using behavioral testing, physiological recording of neural activity, and neuroanatomical tract tracing to ask, what are the neuroanatomical pathways for the formation of emotions and emotional memories? How do we learn and remember emotions? These studies have crucial applications for personnel training, job performance and mental health, and address such questions as: How can emotions, such as fear, facilitate or undermine the training process? Do emotionally stressful situations affect our ability to remember facts, retrieve information, perceive events and objects? How can we better diagnose and treat emotional disorders which undermine performance? How can we enhance attentiveness and memory in stressful situations?

NYU's special strengths also lie in the infrastructure it has established to promote multidisciplinary brain research that incorporates experimental, theoretical, and computational components. As an example, the Sloan Center for Theoretical Visual Neuroscience fosters joint research that harnesses the tremendous recent advances in computational speed, size and memory to effectively revolutionize the power of quantitative analysis to address fundamental problems in neurobiological systems. The Center houses faculty with joint appointments in neural science (Arts and Science) and mathematics (Courant Institute of Mathematical Sciences), supports neural science trainees with backgrounds in the physical and mathematical sciences, and fosters a range of multidisciplinary projects which include analysis of neural and network dynamics of the visual cortex; the nonlinear dynamics of the thalamus and other neural structures; analysis of the visual perception of occluding objects; brain imaging and adult brain plasticity.

CLEM will bring the University's many strengths in these areas more fully to bear on the challenges and opportunities that multidisciplinary studies present. The Center will provide an organizational identity, core resources, and common focus for the university's efforts. For students, it will provide an educational forum to apply knowledge gained in one discipline to problems in other disciplines. For researchers, the Center's synergistic linkages between basic science departments, mathematical and computational units, and biomedical departments will encourage intellectual cross fertilization and will permit the consolidation of individual efforts in multidisciplinary but conceptually coordinated efforts. For colleagues in the fields of technology, education, and medicine, the Center will facilitate connections with life scientists and enhance the translation of research knowledge into commercial and educational applications and health care.

CLEM will be an interdisciplinary unit linking faculty, students, programs and resources from several schools of New York University. These are the Faculty of Arts and Science, the Courant Institute, School of Education, and School of Medicine, including its Skirball Institute of Biomolecular Medicine and the associated Nathan S. Kline Institute Center for Advanced Brain Imaging. To be housed at the University's Washington Square campus within the Faculty of Arts and Science, CLEM will coordinate laboratory research and training in fundamental neurobiological, psychological, and computational studies of the nervous system. The enhanced research and training that will be possible will attract public and private

funding above and beyond the substantial funds, honors and recognition already awarded to the University's researchers, and will support the center's continued growth and development.

Mr. Chairman, this concludes my remarks. I thank you for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) represents over 530 baccalaureate and graduate nursing education programs in senior colleges and universities across the United States.

This statement presents AACN's fiscal year 2000 appropriations recommendations for nursing research and education. AACN thanks the members of this subcommittee for the fiscal year 1999 funding levels for the National Institute of Nursing Research (NINR) at NIH, the Nurse Education Act (NEA) (Public Health Service Act Title VIII), Scholarships for Disadvantaged Students (PHSA Title VII), the Agency for Health Care Policy and Research (AHCPR), the National Health Service Corps (NHSC), and others. These needed funds are being well spent to improve the public health.

For NINR, AACN recommends an increase of $18.523 million over the Administration's fiscal year 2000 budget to $90.2 million, the professional judgment budget. For AHCPR, AACN asks for funding of $188 million. For fiscal year 2000 for the NEA, AACN respectfully requests an increase to $74.6 million. For SDS, we seek an increase to $21.3 million. For NHSC, AACN suggests $85.8 million for the scholarship and loan repayment program for fiscal year 2000. AACN endorses the fiscal year 2000 overall NIH recommendation of 15 percent made by the Ad Hoc Group for Medical Research Funding. AACN agrees with the recommendation of the Health Professions and Nursing Education Coalition for fiscal year 2000 of $316 million for PHSA Titles VII and VIII. AACN also advocates appropriate fiscal year 2000 funding levels for Higher Education Act programs that serve nursing students at the undergraduate and graduate levels, such as Pell Grants, Perkins Loans, Federal Work-Study, TRIO, and GAANN. AACN's reasons follow.

NATIONAL INSTITUTE OF NURSING RESEARCH

Funding NINR at $90.2 million, the professional judgement budget level, would support significant new research opportunities such as: enhancing adherence to diabetes self-management behaviors; prevention of low birth weight in minorities; improved care for children with asthma; managing symptoms in AIDS and cancer; and expanded opportunities for pre- and post-doctoral training in nursing research. Seeking an increase of $20 million over the previous year is not an extreme goal: For fiscal year 1999, NIH's Center for Alternative Medicine received a $30 million increase.

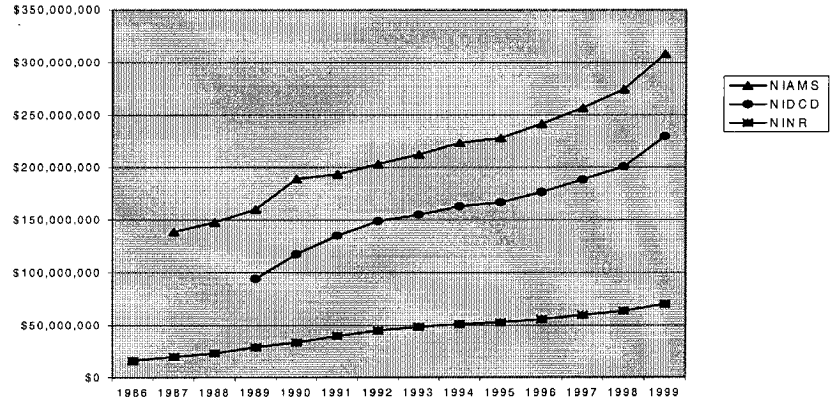
Nursing research contributes significantly to wellness and health outcomes.—The National Institute of Nursing Research performs a wide span of clinical research, developing and testing interventions for promoting health and preventing disease. NINR research has made a difference by identifying ways, for example, to reduce high blood pressure in young urban African-American men at high risk for cardiovascular disease, to help teach children how to prevent and manage their asthma symptoms and to identify pain reducing drugs that work better for women. Nursing and its research are relevant to virtually every condition and disease within the health care delivery system. Indeed interdisciplinary research partially funded by NINR increases the value of NIH research and is complementary to biomedical research.

The following study is one example of how NINR research improves outcomes and cost effectiveness.

Today's shorter hospital stays may be based on hopes of saving money, but they mean that patients are sicker at discharge and need more support at home. NINR funded a project for comprehensive discharge planning and follow-up programs using visits and telephone contact by advanced practice nurses. The study improved patient outcomes and decreased the cost of care and the likelihood of readmissions. Originally developed with a focus on mothers and low birth weight infants, the model of care tested in this study was expanded to elderly patients with complex medical and surgical conditions. Mary D. Naylor, PhD, RN, of the University of Pennsylvania School of Nursing was the principal investigator on this study, and was the lead author on a paper in the February Journal of the American Medical Association that described the results. The study used Advance Practice Nurses (APNs) to work with the patients, family members, and other health care providers

to plan the discharge from the hospital and follow-up care for high risk patients (mean age 75) in the Philadelphia area. The objective was to increase patient and caregiver ability to manage unresolved health problems. This study showed that compared to a control group that had standard discharge planning and home follow-up, intervention group patients were less likely to be readmitted to the hospital, have fewer multiple readmissions, and fewer hospital days per patient. Impressive as the outcomes were, the study also showed that Medicare saved $600,000 in the APN-managed intervention, a per-patient savings of over $3,000. This study showcases the value of nursing research supported by NINR: improved outcomes for high risk hospitalized elders and savings for the Medicare system. This JAMA article has generated considerable interest from providers and managed care systems—all considering this model for implementation.

NINR is one of only two National Institutes of Health (NIH) institutes since 1995 to receive growing numbers of research proposals.—Unfortunately, NINR is projecting that it will only be able to fund 19 percent of its peer-reviewed, approved applications in fiscal year 1999, compared to the NIH projected average of 33 percent. NINR has disproportionately slow growth compared with NIH in general. Since 1986, NINR received only $55.5 million, or 0.5 percent of the total NIH growth of $10.3 billion. Low funding limits NINR's ability to support research and training. NINR's small base operates as a penalty and suppresses its rate of growth. NINR is the smallest institute at NIH with $69.82 million (FY 1999). The next lowest funded institute (Deafness) receives more than 3 times as much money ($229.8 million). This low funding base limits NINR's ability to support research and training. NINR also received the smallest budget increase (10 percent) in fiscal year 1999. NIH received an increase of 14.7 percent with some institutes receiving as much as 15.9 percent on much larger bases. (For example in fiscal year 1999, an 11.5 percent increase for the National Institute of Child Health and Human Development, whose total fiscal year 1999 funding is close to the average of all funding for NIH institutes, equaled $77.5 million, but a 10 percent increase for NINR equaled just $6.4 million.) A small percentage increase on such a low base means a very small dollar increase for the science of nursing. Given the importance of nursing research and the need for research training, as shown by exciting clinical examples, this trend must be changed.



The graph shows funding in dollars from inception of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Deafness and other Communication Disorders, and the National Institute of Nursing Research. As you can see, the chart demonstrates the way in which low initial funding and small percentage increases have adversely affected NINR's ability to fund nursing research and training.

NINR has been designated as the lead institute at NIH to coordinate research on end-of-life care, a new initiative that requires adequate financial resources.—End-of-life issues are critically important to our aging patients and their families. End-of-life care utilizes many of the skills of nursing such as management of pain, handling of chronic conditions, and family counseling.

NINR must be able to increase the number of nurse scientists to meet the Nation's health challenges.—In 1994, a National Research Council report urged a substantial increase in the number of nurse researchers, but NINR has not reached even half of the proposed figure. There is a scarcity of nurses with doctoral degrees compared

to other research professions. NINR supports minority and disadvantaged students and investigators. In addition, there is a graying of nurse researchers and a strong need to prepare and bring to maturity a sizable cadre of nurse scientists in the future.

NINR supports research in two Institute of Medicine high priority areas: clinical research and behavioral research.—Clinical research may be more expensive because it involves working directly with patients (as opposed to laboratory research), but it is just as important to the discovery of knowledge and its application to specific conditions. Behavioral research is also a focus for nursing investigators studying social support, health promotion, self-esteem, stress and others.

NINR's Core Centers focus on major concerns of nursing including symptom management (University of California—San Francisco), care of the chronically ill (University of Pittsburgh [PA] and University of North Carolina, Chapel Hill), serious illness (University of Pennsylvania), gerontological nursing interventions (University of Iowa), and women's health (University of Washington). The Core Centers promote outreach activities to disseminate findings and implications. While the Centers are relatively new, they have provided valuable knowledge on patient care issues.

NINR's research agenda focuses on helping patients deal with pain, maximizing the quality of life of people living with chronic conditions or the physical disabilities of stroke, avoiding low birth weight babies, and maternal and child health. For instance, a University of Illinois-Chicago NINR project is examining ways to strengthen respiratory muscles in patients with chronic obstructive pulmonary disease. A University of Arkansas NINR grant has produced ways to improve knowledge on the ability of nursing home residents to achieve their activities of daily living thus reducing their need for assistance. A Florida Atlantic University project seeks to find ways to improve the quality of life and to reduce the care costs for Alzheimer's disease patients by using exercise and special monitoring. A Johns Hopkins University (MD) NINR project has investigated several interventions to reduce the risk of high blood pressure in young black men, a common concern in this population. A University of Mississippi Medical Center project funded by NINR is supporting an interdisciplinary research team to examine treatment of blood clots and tumors. NINR grants to schools in New York are examining childhood asthma and the side effects of chemotherapy.

A number of major national nursing and other organization support better funding for the National Institute of Nursing Research. The Tri-Council for Nursing (AACN, American Nurses Association, National League for Nursing, American Organization of Nurse Executives), the Coalition for Nursing Research Funding (32 members), and the Doctoral Dean's Group for Nursing Research Funding (31 members) all advocate a substantial increase in funding for the National Institute of Nursing Research.

THE NURSE EDUCATION ACT

The Nurse Education Act programs serve critical public health objectives. AACN seeks an increase in NEA for fiscal year 2000 to $74.6 million. NEA appropriations for fiscal year 1999 were $67.855 million.

Funding for nursing education should be stable.—Higher education programs for professional nurses operate on the basis that a student will study for two, three or more years. Highly trained faculty are hired in what has become a very competitive market for people with the background needed to educate baccalaureate and advanced practice nurses for primary care. Funding to run this type of system should be stable; otherwise skilled faculty will be lost and students will face obstacles in completing on time. In fact, AACN knows that there are shortages of some types of nurses in parts of the U.S. right now.

Funds for nursing education should be sufficient.—The Nurse Education Act is important because it supports innovations in education that enable schools to infuse their graduates with skills needed by today's changing health care system with its emphasis on primary care and health promotion. The NEA has supported over 50 percent of currently operating nurse-managed centers. All 28 NEA supported centers are in medically underserved areas, with 32,000 primary care service visits in 1995. The NEA helped increase the number of minority nursing graduates by 24 percent over the past 5 years.

THE NEW NURSE EDUCATION ACT WILL WORK FOR BETTER HEALTH CARE

The Nurse Education Act (Public Health Service Act Title VIII) helps schools of nursing and nursing students prepare for an evolving health care delivery system. The NEA was reauthorized in 1998. The new NEA (Public Law 105–392) offers expanded flexibility through:

Advanced Education Nursing Grants (Sec. 811).—Grants to schools to train advanced practice primary care nurse practitioners and nurse midwives. Also provides grants to educate master's and doctoral students as clinical nurse specialists, public health nurses, nurse administrators, faculty, nurse anesthetists, and non-primary care nurse practitioners. Includes traineeships for master's and doctoral students with a limit of 10 percent of appropriations for doctoral traineeships.

Workforce Diversity Grants (Sec. 821).—Grants to increase opportunities for nursing education for disadvantaged students including underrepresented minorities by providing scholarships, stipends, pre-entry preparation, and retention activities. Grantees are responsible for accomplishing the objectives of their grants.

Basic Nurse Education and Practice Grants (Sec. 831).—Grants to schools of nursing to strengthen basic nurse education and practice with seven priority areas: expanding nursing practice in non-institutional settings to increase access to primary health care; training for care of underserved and high risk populations, education for managed care, developing cultural competency, expanding baccalaureate enrollments, increasing nursing career mobility, and nursing education in informatics and use of distance learning.

SCHOLARSHIPS FOR DISADVANTAGED STUDENTS

Scholarships for Disadvantaged Students is a PHSA Title VII program (Sec.737) that provides funds to disadvantaged and minority health professions students. Law directs 16 percent of the funds appropriated to nursing students. This program is the major federal scholarship source for undergraduate nursing students. The majority of SDS recipients are minority students. AACN recommends that SDS be funded at $21.32 million for fiscal year 2000, a 10 percent increase. (There is also an education loan repayment program for nursing faculty from disadvantaged backgrounds. (Sec.738)

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

AACN recommends a 10 percent increase over fiscal year 1999 for AHCPR to $188 million in fiscal year 2000. AHCPR's mission is critical to wise utilization of health care dollars because it seeks to discover and to publicize the most effective health care interventions.

NATIONAL HEALTH SERVICE CORPS

AACN suggests a 10 percent increase over fiscal year 1999 for the National Health Service Corps Scholarship and Loan Repayment programs (PHSA Title III) to $85.8 million for fiscal year 2000. This program seeks to attract health professionals to practice in Health Professional Shortage Areas that lack such providers. Many of those areas are rural, and have difficulty attracting and retaining caregivers.

CONCLUSION

In summary, AACN respectfully recommends the following appropriations for fiscal year 2000:

[In million of dollars]

National Institute of Nursing Research	90.2
Nurse Education Act	74.6
Scholarships for Disadvantaged Students	21.3
Agency for Health Care Policy and Research	188.0
National Health Service Corps Scholarship/Loan	85.8

AACN asks the subcommittee to consider these recommendations and will provide additional information upon request.

PREPARED STATEMENT OF PATRICE O'TOOLE, ASSISTANT DIRECTOR, FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL, AND COGNITIVE SCIENCES

Mr. Chairman, members of the Subcommittee, my name is Patrice O'Toole. I am the Assistant Director of the Federation of Behavioral, Psychological, and Cognitive Sciences. I am testifying today on behalf of the scientific societies that comprise the Federation. I am also speaking on behalf of the American Educational Research Association, the American Psychological Association, and the Consortium of Social Science Associations. Our organizations contain most of the scientists who carry out the nation's educational research and many of the scientists who carry out its

health-related research. My testimony will, therefore, be directed at the funding requests for those two areas of research.

OFFICE OF EDUCATIONAL RESEARCH AND IMPROVEMENT

As you know, the authorization for the Office of Educational Research and Improvement (OERI) at the Department of Education will expire during this Congress. In considering the fiscal year 2000 budget request, some members of Congress have justifiably questioned officers of the Department of Education about how well OERI has served its dual charges of research and improvement during the nearly-five years of its current authorization. The answer to their question is not simple. Some of the hopes that were placed in OERI when it was restructured under that authorization have not been fulfilled. But it is fair to argue that we do not know whether OERI is capable under the current structure of fully meeting its charges because two critical events intervened that make OERI's record difficult to interpret. Now that a properly appointed and very experienced leader is in place at OERI, some of the ill effects of those two events may be alleviated. It is an opportune moment to see that OERI has the resources to succeed in its important missions.

The first critical event was Sharon Robinson's departure from her post as Assistant Secretary for Research and Improvement. Dr. Robinson was a strong administrator, and she had vision. Congress, the research and teaching communities, and her staff were delighted to see rapid development during her tenure as the first Assistant Secretary to head the restructured OERI. But her departure left OERI without an officially appointed administrator for nearly two years at just the time that the programs and processes she set in motion should have begun to mature.

The second crippling event was the departure of much of OERI's senior staff at about the same time Dr. Robinson left OERI. You will recall that in order to reduce the size of the Federal workforce, early retirement packages were offered at a number of agencies at that time. OERI had many senior personnel, and it made good economic sense for them to accept early retirement. Unfortunately, their departure also meant that just as it was losing its able leader, much of the institutional knowledge, the deep expertise, at OERI was also being wiped out. OERI went through the middle third of its authorization period with what amounted to a sack over its head and an arm and a leg tied behind its back.

There was little flexibility to permit rebuilding the OERI workforce, and there was no one with authority to rebuild it even if the opportunity had been present. The remaining staff kept the ship afloat, but had no sanction to set its course. That the staff has fulfilled as much of OERI's promise as it has under these circumstances is a credit to its dedication. That OERI has not fully met its promise must be understood in context.

Now, at long last, OERI has a duly appointed Assistant Secretary, Kent McGuire, who has a wealth of experience in administering funding programs for educational research and improvement. It is not a time to punish OERI for not operating optimally over the past two years. Rather, it is a time to take advantage of new leadership by seeing that OERI receives the resources to do its job well. The administration has requested a level of funding that we believe would make it possible for Assistant Secretary McGuire to reestablish OERI's course toward stimulating solid educational research and translating the knowledge derived from it into practices that are effective and widely used. We support the administration's requested funding level, and agree that the new initiatives proposed by the administration are reasonable as well as important. We are concerned, however, that the new initiatives not be undertaken through new bureaucracies that are not part of the current OERI structure. The OERI Institutes were established to provide a management framework reflective of the major areas of enduring challenge to educational research and improvement. The proposed initiatives fit well within that framework and should be administered through the institutes with the research being carried out through the mechanisms now in place. Those mechanisms are field-initiated research, research centers, and regional laboratories. The logic behind this structure is that it forms a pipeline from basic research, to applied research, to demonstration and testing, and finally, to use in the classroom. The initiatives proposed by the administration would lead to research that is important for the improvement of education, but if it is to actually produce improvements, it needs to occur within the system that was designed to turn scientific knowledge into effective practices.

In that regard, we are particularly excited by the administration's request for funds to continue the Interagency Educational Research Initiative. While the National Institutes of Health and the National Science Foundation have supported research that is of tremendous importance to education, much of the knowledge that has been produced has not moved from the scientific to the educational community.

In large part that has not happened because neither NIH nor NSF possesses the pipeline from the laboratory to the teacher in the classroom. OERI has the pipeline. That is why the union of OERI, NSF, and NIH in a joint educational research program is worthy of very strong support. We urge you to honor fully OERI's funding request for this initiative, and we recommend that the Subcommittee add funds to the National Institute of Child Health and Human Development budget so that NICHD can be a full partner in the initiative. It is our understanding that funds for the initiative were in the NICHD budget that went to OMB, but that they were removed at OMB. Each agency in the partnership has a unique role to play in making this initiative successful. Each agency should have the funds to do its part.

In summary, we urge you to recommend that Congress support the administration's request for $540.3 million to support OERI's research, statistics, assessment, dissemination, and educational improvement activities and that new research initiatives be administered through the existing institute framework.

NATIONAL INSTITUTES OF HEALTH

The administration is requesting a 2.1 percent increase this year for the National Institutes of Health (NIH). This would increase NIH's budget from $15.6 billion to $15.9 billion, an increase of $320 million. The Federation is concerned about the administration's incremental proposal for NIH. Last year, the administration did offer an unprecedented increase of 8.4 percent for NIH and Congress took that a step further and approved a 15 percent increase. But under the administration's fiscal year 2000 budget proposal of a 2.1 percent increase NIH will not be able to sustain it's current research portfolio let alone encourage future innovative scientific research. A 2.1 percent increase will not sustain the research begun within the past few years.

The Federation along with other scientific organizations and key members of Congress is asking the subcommittee to recommend a larger increase of 15 percent for NIH. This increase would continue Congress' commitment toward doubling NIH's budget within the next five years. We base our request for this substantial increase on two observations.

The first is that the pace of discovery in the full spectrum of health sciences is accelerating, and the country needs to keep that momentum going. The second is that health care costs are at crisis proportions in this country, and one of the most important ways to control those costs is to find better ways to keep people healthy. The ultimate purpose of health research, including health research in the behavioral and social sciences, is to make the citizens of this country healthier throughout their life span.

Some of the most significant advances in science in recent years have been from research in genetics and neuroscience. The work being done in these areas is a prime example of how basic genetic and neuroscience research is contributing to our understanding of a number of diseases, such as Parkinson's, Alzheimer's, drug addiction and diabetes. Scientific advances in the biology of brain disease have been possible because of new methods for the study of the nervous system, such as neuroimaging.

Understanding and identifying the molecules that guide the formation of the brain is allowing neurobiologists to visualize how the developing nervous system organizes itself, to explain complex behaviors, and to describe neurological and psychiatric diseases with a new level of precision. However, equally important is the role that behavioral, psychological, socio-cultural, and environmental factors play in health. Our beliefs, our emotions, our behavior, our thoughts, our family and cultural systems, our socio-economic status, as well as the environmental context in which we live, are all as relevant to our health as our genetic inheritance and our physiology.

The emergence of cross-disciplinary collaboration has been a major component in the fast paced research developments in these arenas. Across the NIH-supported sciences, the growing tendency for scientists from many disciplines to come together to solve research problems has shown significant results. AIDS has not been cured, but research has shown how a mixture of treatments can ward off the worst effects of AIDS, for many years. These treatments involve the use of a variety of drugs in combination and they involve a demanding level of discipline on the part of the patient to take the medications properly—-a discipline that can be trained by application of techniques developed through behavioral research.

Similarly, recent NIH-supported behavioral research has produced useful new knowledge, including a better understanding of basic behavioral and social processes and how they interact with biological processes. This understanding is coming from many lines of research: studies of lifestyle choices, dietary habits, the desire and

ability to maintain exercise or medication regimens, psychological functioning, and influences of one's social and cultural environment on behavior.

All these lines of research converge to give us a picture of the factors that can affect an individual's ability to remain healthy or to recover from disease or to function well despite a chronic condition. And that knowledge leads to treatments and other interventions to maintain health throughout the life span.

NIH's Office of Behavioral and Social Sciences Research (OBSSR) has been pivotal in supporting these studies and translating the findings into effective prevention and treatment strategies. OBSSR, under the purview of the Office of the Director of NIH, coordinates all the institutes and centers in marshaling their individual resources to collaborate on behavioral and social sciences research. OBSSR was congressionally mandated in 1993 and began operation in 1995 with a primary mission to foster the development of cross-disciplinary communication and research collaboration among behavioral and social sciences and between the behavioral and social sciences and biomedical sciences. OBSSR's efforts are assuring that development of effective behavioral interventions is keeping pace with technological advances.

OBSSR has been operating for several years with a small staff and a small budget. Last year Congress approved a $10 million increase for OBSSR to continue its efforts to encourage cross-institute collaboration and research in the behavioral and social sciences. The President's budget request for OBSSR for fiscal year 2000 is $13.2 million—-a nominal increase above OBSSR's current budget of $12.66 million. The Federation supports an additional $10 million increase for fiscal year 2000 for OBSSR. This increase of approximately 22 percent combined with the President's request would bring OBSSR's total budget close to $24 million and would significantly augment OBSSR's ability to coordinate research across institutes. This is an efficient use of resources and a beneficial mode of operation, because it links areas of related knowledge that might otherwise remain separated.

A prime example of the application of behavioral intervention in concert with the use of medicines has to do with deadly diseases that are reemerging after decades of dormancy in this country. Tuberculosis is the example that comes to mind. When medications are misused, the result is not only that the patient's disease cannot be controlled, but also the bacterium that causes the disease develops resistance to medication making the disease more difficult to treat. These diseases are resurfacing at an alarming rate throughout the country. We face a serious challenge with respect to these diseases and our ability to curb them may become the public health problem of the 21st century.

OBSSR sees adherence to medication and treatment regimens as an area ripe for collaborative research in fiscal year 2000. In fact, since the 1970s only 13 randomized and controlled studies have been conducted on adherence and treatment effects. Developing strategies and interventions for patients and doctors is critical to curbing the emergence of more drug-resistant infectious diseases. In response, OBSSR plans to develop an RFA to encourage research on understanding and improving adherence to treatment on all levels.

Behavioral and social scientists working with other scientists and health care providers can find answers to this growing problem. COSSA is holding a congressional briefing on this very topic, April 16. Another path that OBSSR sees to resolving this problem is to support medical schools in incorporating research findings from behavioral and social scientists into medical education. As it stands now, medical schools do not routinely address nor recognize the importance of behavioral and social aspects of diseases. OBSSR is developing an RFA to enable medical schools to include evidence-based behavioral treatment approaches in their curricula.

NIH funding has permitted us to use research wisely, that is, in the combinations that will be most efficient in reaching solutions to typically multifaceted health problems. To continue successful biomedical and behavioral research at this level requires an ongoing commitment by Congress to find the resources for expanding NIH's budget without cutting the budgets of other important public health programs. We understand that the current budget caps make it difficult to prioritize needs, but we strongly urge the subcommittee to take whatever means is necessary to find the funds to maintain a high level of support for NIH.

With increased support, the current pace of discovery and collaboration can be sustained. The largest per person expenditures for health care occur near the end of life. One goal of research is to understand what interventions through the life span will have the greatest promise of assuring that the period of great illness before the end of life is minimized. The National Institute of Child Health and Human Development (NICHD) conducts research on human growth and development from conception through birth, infancy, childhood, adolescence, reproduction, and through maturity to old age. As such, NICHD addresses some of the most important health and development problems facing our children and families. Based on this broad

spectrum of research, we believe that NICHD's fiscal year 2000 budget should be substantially increased by approximately 22 percent, bringing its budget up to $915 million. Historically, NICHD has consistently been one of the lowest funded institutes even though it conducts research that has immediate, proven and successful applications through behavioral intervention. We urge the subcommittee to press for higher funding of NICHD.

Behavioral research has a large role to play in contributing to the nation's health, because controllable choices and behaviors in life have a heavy impact on the quality of life. Obviously, such behavioral choices as to smoke or not to smoke and what foods and quantities of food to consume are among the most important choices we make in determining our health. But each of us knows how difficult it is to do the right thing.

Behavioral researchers in cooperation with nutritional researchers, neuroscientists, epidemiologists and a host of other specialists are working to find ways to make it easier for people to make the right choices about their health. The payoff for finding solutions to these problems will be not only a healthier population, but also the shrinkage of health care costs to a manageable size without sacrificing the well-being of the country's citizens. Through research it is becoming possible to maintain good health and keep health care costs down at the same time.

We strongly urge the Subcommittee to recommend a 15 percent increase for NIH because the investment in knowledge will result in healthier citizens and health care cost savings that far exceed the research investment. Slighting research will assure that rising health care costs will remain among our most serious national crises.

We thank the Subcommittee for the opportunity to present our views.

PREPARED STATEMENT OF CHIEF MATER SERGEANT (RET.) JAMES E. LOKOVIC, DIRECTOR, MILITARY AND GOVERNMENT RELATIONS, AIR FORCE SERGEANTS ASSOCIATION

Mr. Chairman and distinguished committee members, on behalf of the members of the Air Force Sergeants Association, thank you for this opportunity to discuss the vitally important issue of Impact Aid funding within the context of the Department of Education's (DoE) fiscal year 2000 budget. The primary mission of this association is to promote and protect the quality of the lives of all enlisted Air Force, Air National Guard and Air Force Reserve members, retirees, and their families. Impact Aid is an important program for those military families we represent as it zeroes in on the quality of the education programs provided to their children. It is ironic that the administration that purports to focus so much on education has chosen to once again slash Impact Aid dollars—by $128 million in his fiscal year 2000 budget. The implicit statement in these such decisions is that military children are a lower priority than others in our nation. We urge this committee to once again force the administration to do what is right in taking care of military families and children.

BACKGROUND

Impact Aid appropriations provide assistance to school districts for several reasons. Impact Aid is provided to local communities in light of the presence of civil servants, Native American children, low rent housing, and—in 40 percent of the total appropriation—to school districts impacted by the presence of military children. It is on behalf of these military children that I speak this afternoon. Simply put, Impact Aid is the federal government's obligation to the children of military personnel.

From the time of the Truman Administration, our government has recognized the unique sacrifices, transient nature, and special requirements of military families. Impact Aid has helped compensate for a funding inadequacy in local districts which educate military children. This shortfall is created by an inadequate contribution on the part of the military installation and military members to local taxes which fund public education.

For military children, funding is provided at two different levels; one level (3a) if the parents of a student live and work on federal property and another level (3b) when a parent works on federal property but lives in the community as a renter or homeowner. Local education agencies receive $2,000 for each 3a student and $200 for each 3b student. Impact Aid is an excellent example of federal funds going directly to the targeted program with little bureaucratic red tape. The funds go directly to schools to serve the education of military children, and local boards of education decide how these funds are to be spent.

Certainly, the children of military members lead a unique life, fraught with challenges unlike those faced by most of the rest of this nation's youth. They typically

change schools often, repeatedly being uprooted and having to readjust to new communities and friends. One very necessary annual budget action has been to recognize these young men and women by providing funding through Impact Aid to the local school districts which educate them. This federally funded program supplements the cost of educating military children in grades Kindergarten through 12.

Interestingly, for these children, the return on our government's investment goes beyond the normal focus on an educated citizenry. These children are unique in that approximately 50 percent of current active duty personnel grew up in military families. In that sense, Impact Aid directly affects the quality of our nation's future military leaders.

Without question, the dynamics of the military family are in transition. The all-volunteer force has had a dramatic impact on the new military and its demographics. More personnel are married. Approximately 65 percent of military spouses are employed, especially within enlisted families. There are more single parents in our military today. There has been a steady increase in the number of military preschool age children. Active duty personnel have about one million children younger than 12 years of age.

Today, there are increasing pressures on military families with the very vigorous military operations tempo and executive decisions to involve the U.S. military in peacekeeping/police actions around the world. Military parents are now constantly "on the bubble," subject to short-notice deployments. As the national leadership has significantly reduced the size of the military, it has also significantly increased the mission requirements. On top of that, further anxiety exists with the uncertainty of downsizing, privatization and outsourcing. With all of the other challenges of military life, it is important that, at the least, we are committed to provide a quality education for military children. It is a high priority for military families it is a readiness and a quality-of-life issue. As our military personnel are deployed, they should not have to worry about whether their children are taken care of.

WHY MILITARY CHILDREN NEED THE SUPPORT OF IMPACT AID

In recent years, districts with a large number of military children have found there is inadequate education funding which has required higher property tax rates (which generally fund local school systems). Clearly, localities, should not be punished because of the location of a federal facility. The administration, which ultimately assigns these families, has an obligation to support them. And yet, it is ironic how little attention has been paid to military families during administration discussions on nationwide educational funding and expansion. The children of our military members must be considered in these plans. Impact Aid is the most proper way to reflect the need to protect their (and local community) interests.

We would like to remind this committee that there have been attempts in the past to charge "enrollment fees" to the parents of military children. For enlisted families, in particular, such an eventuality could be devastating since they are paid the least. Military parents expect that the federal government will act in the best interests of their families. If there is any group among our nation's families that should earn an extra measure of governmental support, it is those who serve our nation and are transferred at the pleasure of the government. However, we fear that continued diminishment of the program will result in other attempts by communities to charge fees to make up for education funding shortfalls. It would be wrong to penalize military families simply because the government stations the family at a particular location.

The problem could become even more severe. As the military proceeds with the privatization of military housing, and if that housing is not considered "federal property," then students would be classified as 3b students, providing only $200 per student to the local education authorities. This could create tensions between the residents of heavily impacted communities and military facilities in those communities. Area civilians could reasonably question why their children's education must suffer. This is an area that requires careful congressional observation. The options are to fully fund and continue this important aid, or to underfund it (as has recently been done) hoping that Congress will remedy the situation.

Once again, the administration followed its pattern in recommending deep cuts in the Impact Aid program. Why is the basic education of military children such a low priority for this administration? If our military children don't receive the quality education they need in elementary and high schools, we won't have to worry much about college incentives.

As funding for school districts that serve military children has been reduced, one of the first areas that has been affected is new construction and upkeep of the school buildings. Continual cutting of the Impact Aid program has had a tremendous im-

pact on the local schools. Due to the drawdown, some schools have experienced substantial increases in students and are having a difficult time accommodating the growth. Many of the school facilities used by military children were built in the 1950s and today are in need of repair, ADA accessibility, asbestos removal, etc. The aging facilities and shortage of upkeep and maintenance has put many of the schools in dire need of attention.

During the past 18 years, while the number of students served through Impact Aid has remained the same and the consumer price index has increased by 70 percent, Impact Aid funding has not been treated as a priority. Without question, full funding for Impact Aid will greatly assist in insuring the children of our military personnel a quality education without endangering or compromising the budgets of local school districts.

THE REQUEST

We believe it's very simple, Mr. Chairman—the federal government must pay its tax bill to school districts for the education of military children. Originally instituted in 1950 and fully funded until 1970, Impact Aid is now regularly underfunded, and military associations and Congress go through an annual drill to overcome the administration's intentions. As we indicated, the result of such a lack of commitment to military children has resulted in school districts facing many financial crisis and the prospect of possible closures.

On behalf of those that AFSA represents, I recommend full appropriations to fund Impact Aid. We fully expect that the Department of Defense (DOD) will once again find itself required to protect military children from the Department of Education's intentional under funding of Impact Aid. For more seriously impacted, high need districts, we ask that this committee recommend an Impact Aid appropriation of $944 Million. Those that have tracked Impact Aid since the 1950s and the escalating costs of education have indicated that this figure will fairly supplement local school districts for situations created by the federal government.

It is the position of this association that the time has come to set an automatic funding mechanism in place to avoid having to revisit this issue each year. A look at the history of Impact Aid appropriations shows a remarkable disparity between overall DoE spending and Impact Aid appropriations. Since 1950, our nation's overall education budget has increased at a factor of more than 94 times. During the same period, Impact Aid appropriations have increased at a minor fraction of that. The simple questions we need to consider in determining the right thing to do are these: "Do we, as a nation, commit to assisting local school districts who educate the children of our military?" " If so, can we arrive at a level of spending that results in quality education without endangering local budgets?" And finally," Do we accept that in stationing a military family there, our government also incurs an incontestable obligation to supplement local school districts for each student so educated?" If so, we urge this Congress to arrive at an annually applied formula, using $944 Million as a baseline, which becomes an automatic part of every affected appropriations budget. We believe that paying for those items that reflect doing the right thing should be automatic spending priorities.

As Senator Chuck Hagel (R-NE) recently said, "I am constantly torn between amusement and bemusement as to why we continue every year to be presented with a budget on education that decreases Impact Aid. The same people . . . who are quite distraught that we can't recruit for the military and that the quality of life is deteriorating in the military . . . short circuit the funding process to educate the military children. It makes no sense to me."

We understand the difficult budget choices that you face; however, we believe that the education of military children should not suffer because their families are moved at the convenience and desire of the federal government. Military children should be held in the same high spending priority that this nation affords all other children. We urge this Congress to direct the Department of Education to require full funding for Impact Aid. Mr. Chairman, I thank you again for this opportunity to express our views on this issue. As always, AFSA is ready to support you in matters of mutual concern.

PREPARED STATEMENT OF RON HERNDON, PRESIDENT, NATIONAL HEAD START ASSOCIATION

On behalf of the National Head Start Association, I am pleased to testify in support of fiscal year 2000 appropriations for the Head Start Program, administered by the Department of Health and Human Services under the Subcommittee's jurisdiction.

The National Head Start Association (NHSA) is a private nonprofit membership organization representing over 800,000 children and their families, 150,000 staff, and nearly 2,200 Head Start programs across the country, including the 600 Early Head Start projects and the 35,000 children and families they currently serve.

NHSA supports President Clinton's goal of enrolling one million children in the Head Start Program by fiscal year 2002 and doubling the number of infants and toddlers and their families enrolled in the Early Head Start initiative during that same period. At the same time, it is my duty to respectfully remind the Subcommittee of a promise made to Head Start by President Bush and by both Democratic- and Republican-controlled Congresses. That promise was that, by the turn of the century, Head Start would be fully-funded. Accordingly, NHSA requests the Subcommittee's favorable action on a fiscal year 2000 appropriation for Head Start of $5.507 billion—an increase of $847 million over the fiscal year 1999 program funding level.

While it is the view of the National Head Start Association that the President's requested appropriation level ($5.267 billion, in increase of $607 million) will not yield an increase in Head Start enrollment sufficient to keep the program on the path agreed to in the bipartisan budget agreement enacted in 1997, NHSA is encouraged by the President's leadership in proposing the largest single year funding increase since the inception of Head Start more than 30 years ago. The President's budget will also support an incremental increase in Early Head Start enrollment consistent with the goal of 10 percent of program funds eventually being dedicated to the infant and toddler element of the program, as codified in the 1998 reauthorization of Head Start. The funding levels the NHSA endorses will ensure that services to infants and toddlers might expand without jeopardizing scheduled increases in Head Start enrollment for children age three through compulsory school age.

In addition, we encourage the committee to direct the Department of Health and Human Services to support efforts by local Head Start programs to use expansion funds to deliver quality services to the infant and toddler population where a community assessment evidences a need for such services and the local program has the capacity to meet that need. Such expansion responds to local community needs, separate and apart from the new grant process under the Early Head Start expansion included in the committee bill. When combined with the new grant authority incorporated in the 1998 reauthorization of Head Start for Early Head Start, expansion of existing Head Start programs to serve the needs of younger children is responsive to recent research emphasizing the developmental needs of younger children—needs which can be ably addressed through the Head Start model of comprehensive services.

The National Head Start Association is also pleased to support one critical aspect of this appropriations request—the allocation of more than $300 million to Head Start quality improvement, as embraced in the 1998 Head Start reauthorization.

Research indicates tremendous benefits to the Head Start program as a result of the quality set-aside specified in law. Child to adult ratios, group size, average daily attendance and percent of teachers with degrees have all improved significantly. But the job is not done and we should not compromise our support for quality improvement.

Thanks in major part to the efforts of Chairman William Goodling during last year's reauthorization process, this year's budget request includes a doubling of the proportion of new funds which are allocated to quality improvements.

We urge the Subcommittee to continue its commitment, also specific in the authorizing law, that one-half of the quality set-aside be dedicated to staff salaries and benefits.

The 1998 Head Start reauthorization called for a focus on the professional development of Head Start staff—with a goal of achieving specific credentialing criteria by the end of the reauthorization process (50 percent of classroom teachers nationwide with at least an associate's degree). By no means do we believe that a paper credential alone is evidence of a quality Head Start teacher. But, the ambition of Head Start teachers, staff, directors, and parents to achieve mobility, to reach for betterment, and to gain the tools they need to succeed, must be supported. The dedicated staff who have been the backbone of the most successful programs in the country must be supported—just as Head Start families must be empowered to gain a foothold in the climb from poverty.

While the attrition rates in Head Start projects across the country have seen marked improvement in recent years, low pay and staff turnover remain a constant threat to program stability and quality. In many cases, staff who have served Head Start for 25 or even 30 years are left to retire without any retirement plan. This situation must change if Head Start is to attract and retain high quality staff.

Lawrence County Head Start (LCHS), New Castle, Pennsylvania, has a history of providing quality comprehensive early child development services in Lawrence County for over thirty years. LCHS is very concerned of the numerous unlicensed child care services that are cropping up throughout their service area. Head Start quality must be maintained. With additional funds, one of our initiatives is to utilize the Early Childhood/Child Development Associate (CDA) staff with degrees as trainers for family and group daycare homes. Their county collaboration team is hoping for funds to begin a "countywide credential"—utilizing CDA and Head Start as a springboard to develop county standards. Money is needed to continue this initiative.

Maintaining quality is deterred when salaries are not commensurate with school districts. I am very concerned that the quality of the family support services focus is being eroded during deliberations about Head Start. Let us never, ever, forget that the comprehensiveness is what counts. LCHS is going to lose some very caring, professional staff because of the low salaries.

These 1.5 percent COLA and quality improvement increases have barely been scratching the surface. "How can my employees cope with helping families, when many of them are still eligible for some sort of assistance?" asks the program director. Let us not forget our current employees. High standards must also mean better salaries. In addition, LCHS has a waiting list of over 80 children for this current year. Many of the families are not being serviced by anyone. Families are struggling to find any type of care. Many elementary students are truant because parents are making them stay home to watch siblings so parents can go to work.. Additional funding would also go toward expanding to meet unmet needs in the community.

Pinellas County Head Start (PCHS), Pinellas Park, Florida, is vigorously preparing for the 2003 educational requirements that 50 percent of Head Start teachers nationwide have associate degrees. PCHS is meeting with the local community college to ensure that the community college offers the proper courses, and to ensure that prior colleges courses taking by staff are transferable at the that particular institution. Increased funding would go towards staff compensation for those individuals who have achieved their associate degree and help PCHS to continue to provide those staff members who cannot afford to pay for courses with financial aid. PCHS also helps with staff education requirements by securing TEACH scholarships, a Florida state-level education scholarship that is awarded to individuals who are taken education classes in the State of Florida.

With regard to school readiness, PCHS has really worked to strengthen their transition agreement by adding improvements and submitting it to the Pinellas County School Board. The strengthened agreement was passed and signed by the PCHS director, the school board chairperson and the school superintendent. PCHS has actively involved area "feeder" elementary schools principals and teachers. They have arranged exchange visits for principals and teachers to visit Head Start centers and for children and Head Start staff to visit local schools. Some of these schools include Woodlawn, Rawlings and Davis Elementary schools.

The challenges faced by local Head Start programs are many. But by no means does the Head Start program go it alone. In delivering high quality early care and education services, family support services, home visits, parent education, family literacy services, comprehensive health and mental health services (including services for women prior to, during, and after pregnancy) and nutrition services, local Head Start programs are dependent upon collaboration with other service providers running the gamut from transportation providers to food service firms to child care providers to medical professionals and schools. In each community, the list of partners is different and a function of the unique needs and resources available locally. In the Early Head Start initiative alone, school districts, nonprofit community agencies, colleges and universities, local governments, mental health and health service organizations, and child care providers are among the organizations providing services—much as in the three decade old Head Start preschool program.

Lake County Community Action Project, (LCCAP), Waukegan, Illinois, thanks to help from Congress, secured funds to build a new facility in Waukegan, which is the largest poverty area in Lake County. The new center (there will be a groundbreaking ceremony next month, with the facility ready in 10–12 months) will serve 252 children with wrap-around services and also house parent training capacity. The new fiscal year 2000 funding would allow room for expansion of this facility. Wrap-around services are provided with money from the Community Service Block Grant and the Child Development Block Grant from the state. LCCAP also is receiving help from local corporations to help build the new facility and provide wrap-around services. Increased appropriations would also help with the immediate expansion, 2003 staff educational requirements, safety and security facility improvements, and transportation needs.

Increased appropriations also would help with the continuation of full-day, full-year wrap-around services due to welfare to work. Iowa East Central Train, (IECT), Davenport, Iowa, has a long wait list due to welfare reform, and parents now going back to work and having no adequate child care provided. IECT needs to expand existing services for children and not necessarily expand to serve new children. Wrap-around services are currently being provided with money from the Iowa Department of Education and Department of Human Services. There is now a change in that funding stream for next year and beyond. There are now county empowerment boards that will allot the state dollars on a county level, and the IECT director feels that the money will be cut dramatically. The Iowa Head Start Association did not support the funding stream change due to the outcome it may have on the children. The five wrap-around classrooms with 85 children may have to transition from full-day, full-year to half-day, part-year. IECT also recently received an EHS grant. IECT has very minimal training and technical assistance dollars to train staff. IECT has over 100 staff and 514 children, and for a program that size, there is not enough money to send staff to training. Additional funding would help amend that situation.

The National Head Start Association appreciates this opportunity to reinforce the critical national interest served by supporting expanded Head Start services. With your assistance, we can continue to make a difference in the lives of our most vulnerable children, families, and communities.

In summary, we request:

—A fiscal year 2000 appropriation of $5.507 billion—an increase of $847 million over the fiscal year 1999 appropriation level;

—Within that appropriation, an incremental increase in the amount designated for Early Head Start services; and

—Increasing the annual set-aside for quality improvements mandated in the Head Start authorizing law to $423.5 million of a requested $847 million increase for fiscal year 2000.

PREPARED STATEMENT OF THE ROCK POINT COMMUNITY SCHOOL BOARD

Mr. Chairman and Members of the Committee: The Rock Point Community School Board urges the Subcommittee to adopt report language to encourage the Department of Health and Human Services (HHS) to allow tribal organizations to administer Head Start programs under Public Law 93–638 self-determination contracts.

The Rock Point community is located in an especially isolated area of the Navajo Nation reservation. The community's Head Start program, which is one of 180 Head Start centers operated by the Navajo Nation through a direct grant from the Head Start Bureau American Indian Programs Branch, serves a total of 30 children. Twenty are served at the Head Start center, and ten who live in particularly remote areas receive 1.5 hours of weekly home-based instruction. That said, at least 60 children are eligible for comprehensive Head Start services, based on the kindergarten enrollment statistics for the Rock Point community.

The Rock Point Community School Board has repeatedly asked the Head Start Bureau to consider our providing us with direct grantee status to operate the Head Start program. By becoming a direct grantee, we would be able to run a Head Start program which best suits the unique needs of our small community. Unfortunately, the Head Start federal office refuses to honor our request.

Section 102 of the Indian Self-Determination Act (Public Law 93–638) directs the Secretary of Health and Human Services (HHS) to contract with tribes to operate federally-funded programs for their members.

The Rock Point Community School Board has successfully contracted education programs since 1972 and has continually improved student services during this time period. As such, the Board believes that administering a tribal Head Start program through a self-determination contract would be beneficial. It would decrease the amount of federal bureaucracy that we deal with by allowing us to receive all of our funds directly from Head Start using one funding document and would let us to run our local programs to meet local needs.

Therefore, we request that you include fiscal year 2000 report language that would encourage the Secretary to work with tribes to fully implement the Indian Self-Determination Act so that tribal organizations may contract for such HHS programs as Head Start.

Thank you for your consideration of our request.

PREPARED STATEMENT OF BRENT GISH, PRESIDENT, NATIONAL INDIAN IMPACTED SCHOOLS ASSOCIATION

The National Indian Impacted Schools Association (NIISA) is an association of public schools in Indian country dedicated to quality education and assuring that the United States' obligation to provide resources for educating Indian and Alaska Native students is fulfilled. Our membership consists of public school districts which receive federal Impact Aid funds because of the presence of students from Indian trust lands and Alaska Native lands. Approximately 90 percent of Indian and Alaska Native students nationwide attend public schools.

SUMMARY OF REQUEST

We ask the Subcommittee to recommend the following with regard to the fiscal year 2000 Department of Education budget:

—*Impact Aid Basic Support Payments*.—$754 million for Impact Aid Basic Support payments under Section 8003(b) of the Impact Aid statute. This is the same as the request of the National Association of Federally Impacted Schools and is 7.1 percent over the fiscal year 1999 enacted level. This amount would allow the schools to be paid at 100 percent of LOT.

—*Impact Aid Facility Repair*.—$25 million under the authority of Section 8007 of the Impact Aid statute for payments for facility repair, renovation and construction. This compares to the fiscal year 1999 enacted level and the Administration's request of $7 million. While this is termed a "construction" account in the authorizing statute, the funds are distributed by formula to schools, making the amount individual school districts receive so miniscule that it cannot make a significant impact on facility construction needs.

We strongly support enactment and funding of school construction legislation to assist public school districts who, because of the presence of Indian lands, have little ability to raise revenue.

—*Forward Funding of Impact Aid*.—Impact Aid is one of the few major federal education programs which are not forward funded. Even if we were not experiencing major delays in distribution of Impact Aid funds as we are now, it would be enormously helpful for planning and budgeting purposes for the program to be forward funded.

THE IMPACT AID PROGRAM IN INDIAN COUNTRY

For Indian country, the Impact Aid program is a vital element of the public policy of providing every child a free public education. Signed into law in 1950, the Impact Aid program is one of the oldest federal education programs. Simply put, it provides federal funds for public school operations that would have otherwise been provided by local tax revenues but for the presence of federal property—in our case, lands held in trust by the federal government for Indian tribes. One of the great attributes about the Impact Aid program is that it provides flexible funds to school districts. Because Impact Aid funds are actually in lieu of a property tax base, it is logical that they are not geared toward specific program use.

The Impact Aid program is an example of the U.S. government carrying out its trust responsibility—in this case, for education—for Indian and Alaska Native peoples. Some facts about the Impact Aid program in Indian Country:

—There are over 600 school districts throughout the country which receive Impact Aid funds for Indian lands schools.

—Funds for Indian lands students represent nearly 50 percent of the federal Impact Aid appropriation.

—The Indian Country land base that generates Impact Aid funds consists of 53 million acres of Indian trust land in the lower 48 states and 44 million acres included in the Alaska Native Claims Settlement Act.

—The Impact Aid program provides a formal link between tribal governments and public schools, providing for school district consultation with Indian tribes and tribal communities. This is especially important because public schools are State institutions, but located within tribal boundaries. School districts must consult with tribes and the Indian community to develop Indian Policies and Procedures (IPP). Tribes and parents of Indian students are able to comment on whether Indian students are equal participants in educational programs and school activities, and to request modifications in school programs and materials. Tribes also have administrative appeal rights under the statute.

THE LEVEL OF IMPACT AID EFFECTS STUDENT PERFORMANCE—THE SANTEE SCHOOL EXPERIENCE

We would like to give you an example of how increased Impact Aid funds resulted in dramatic academic improvement for the students of the Santee School District.

On March 17 the House Education and the Workforce Subcommittee on Early Childhood, Youth and Families held a hearing on reauthorization of the Impact Aid program at which Chuck Squier, Superintendent of the Santee School, testified. The Santee School District in northeast Nebraska is made up of entirely Indian trust lands and its students are Santee Sioux. Superintendent Squier testified about the impressive student gains which have been made since his school district has received an increase in Impact Aid funds.

Prior to 1995 the school district had been receiving only 60 to 70 percent of the amount of Impact Aid for which it was eligible. Reading scores had dropped during the previous three years: 1st grade scores dropped from 1.8 to 1.2 GME;[1] 8th grade scores dropped from 7.4 to 5.9 GME, and 11th grade scores dropped from 10.2 to 9.4 GME. In an effort to reverse this trend, the school district formed a Curriculum Committee composed of school staff, parents and other community members. They reviewed current research on ways to improve student reading and decided on a plan of action which included teacher training, a reading management system, multiple copies of books, a daily focus on reading and ninth hour tutoring. Specific programs included reading recovery, accelerated reader, school at the center, foss science, and project read. However, the recommendations of the Curriculum Committee were not able to be implemented because of lack of money.

But when the Impact Aid program was reauthorized in 1994, Impact Aid funding increased for the Santee Sioux school. The school district was able to use that money to leverage additional grant dollars for teacher training and research-based reading programs and the rest of the plan recommended by the Curriculum Committee. The plan was implemented. Students are tested in the fall and in the spring, and the results have been very impressive. Last year, 28 percent of the students in grades 3–12 increased their reading level two grade levels. Another 25 percent of students raised their reading level 1.5 or more grade levels, and 36 percent of students raised their reading level 1 or more grade levels. Particularly gratifying was the 9th grade results, as this class had declining scores for the prevoius three years. Expansions of the schoolwide reading program are planned for next year, along with rewriting the math/science studies/language arts curriculum—financial resources permitting.

The Santee School District program is shared through the Nebraska Native American consortium, which serves 98 percent of all students in Nebraska living on tribal lands.

FORWARD FUNDING

We urge Congress to take the long overdue step of providing appropriations to forward fund the Impact Aid program. Other major education programs, e.g., Title I, IDEA, Bureau of Indian Affairs school operations, are forward funded. School administrators in heavily impacted districts must make very difficult and risky program and personnel decisions for the upcoming school year or the next school year without knowing how much Impact Aid they will be receiving. For many Indian lands schools, Impact Aid is the primary source of school operations funding and the schools would shut down without it. While school administrators cope with this system, it makes much more sense for a school administrator to know 6–12 months prior to the beginning of the school year what its budget will be. When the federal government shut down several years ago, Impact Aid schools had to borrow money just to keep open and had to pay large amounts of interest—tens of thousands of dollars for some schools—for which they were not reimbursed. Some Impact Aid schools are in the same position now of having to borrow money because of problems at the Department of Education resulting in chronically late payments. We know that Congress understands this problem because most federal education programs are forward funded. Impact Aid is a program of basic support for a school, not a narrow categorical program.

We realize that the first year of forward funding will strain the appropriations process as you have to appropriate two years worth of funding. On the other hand, we have a budget surplus and there is support from the Administration and both parties in Congress for increasing federal education funding. This seems like a good time to finally forward fund Impact Aid. If the program cannot be forward funded

[1] GME stands for Grade Means Equivalency.

in total, perhaps the Basic Support and Disabilities portions of the program could be forward funded, or the committee could look at the possibility of a phased-in approach to forward funding.

SCHOOL FACILITIES

School facilities construction and renovation, including making facilities ready for education technology, is a high priority for our organization.

NIISA has and will continue to work with Congress on pending school construction proposals to make them responsive to the needs of our schools—Indian lands public schools. School construction bills have been introduced in a steady stream during the last two Congresses and also the current Congress. We have seen in these bills a growing recognition that there needs to be accommodation for public school districts which have little, if any, bonding capacity (including those schools in the Bureau of Indian Affairs system). For instance, there are now bills which would allow a state to issue school construction bonds (not just the LEA) and which would require the state application to explain how they will assist schools that lack the fiscal capacity to issue bonds on their own. This could be helpful to some school districts with Indian lands. To the extent that a school district has limited ability to generate revenues because of a federal presence (e.g., the existence of Indian trust land or federal property in the school district), there is a clear federal responsibility toward the education of the children attending those schools.

The condition of public and Bureau of Indian Affairs school facilities has been documented in General Accounting Office (GAO) surveys. Because the GAO surveys did not report data specific to Indian lands public schools, our organization, in October, 1996, undertook a survey of school districts which receive Indian lands Impact Aid funding. Some of the findings from the survey, which we have previously reported to this Subcommittee, are:

—65 percent of buildings are over 20 years old, including 38.2 percent over 30 years old;
—$6,872,000 is the average estimated costs necessary for repairs, renovations, modernization and construction to put schools in overall good condition;
—the average cost per student to make school buildings meet health and safety standards is $1,947;
—to accommodate expected increased enrollment over the next 5 years, the schools responding to the survey will need 13.1 percent more space. Within 10 years, the space needs are expected to increase by 27.9 percent;
—71 percent of school districts have had no school construction bond issued since 1985, and 23 percent of school districts have never had a bond issued;
—Of schools with 70 percent LOT MOD and higher, the need for construction, renovation, and repair funding is two thirds higher per pupil than in the other respondents to the NIISA survey. (Note: LOT MOD is a Department of Education measure of need of school districts affected by the presence of federal property);
—42 percent of respondents have unhoused students;
—59 percent of school buildings have inadequate laboratory science space;
—63 percent of schools are not well served for before/after school care.

Thank you for your interest in the need of our public schools which educate children from Indian country. We ask you to always keep in mind the trust responsibility for the education of Indian and Alaska Native children and the federal responsibility regarding school districts which contain Indian and federal property.

PREPARED STATEMENT OF THE NATIONAL MILITARY FAMILY ASSOCIATION

NMFA and the families we represent are grateful to this Subcommittee and to the Senate for its actions on behalf of military children and the Impact Aid Program. We thank all Congressional supporters of Impact Aid, especially the members of the House and Senate Impact Aid Coalitions, for securing another increased appropriation for the program for fiscal year 1999. Your continued support of this program translates into better education for approximately 500,000 military children and several million of their civilian classmates in school districts across the country. Thank you.

THE MILITARY CHILD

NMFA presents this statement on behalf of military families, or more specifically on behalf of military children.

—Military children move every 2 to 4 years and attend an average of five different schools. Since the drawdown overseas, those schools are more likely to be in stateside systems dependent on Impact Aid rather than in Department of Defense Schools.

—Military children come to their new schools with a wealth of experience gained from living in many parts of the world. But, they also frequently come with gaps in their education which their new teachers must quickly fill while moving the rest of the class ahead. Sometimes they are far ahead of their new classmates, adding boredom to the list of reasons why they hate to move to yet another new school.

—Because of varying course standards, school schedules, and state graduation requirements, they sometimes lose credits needed for graduation or they must take state accountability tests on subject matter they never learned. They often enter school too late to win a spot on the school paper or cheerleading squad.

—Because of the high operations tempo of today's military, the military child often has to adjust to the new school, face that week of standardized tests, fight for the spot on the yearbook staff, play the basketball game before a crowd of strangers without the support of their military parent. Worry about the safety of a parent in a place far from home where people are shooting at each other makes for a powerful distraction from the business of education.

Military families want to be involved in their children's education and list education as one of their top Quality of Life concerns.

—They serve as room parents, vote for school board members, help wire a classroom for computers which often won't be installed until after they've moved away.

—They master the bureaucracy of one school system, fighting to get their child placed in proper programs in a timely manner, only to have to start all over again at the next school with a different procedure and a different set of tests.

—They receive their child's report cards via e-mail on a ship in the middle of the ocean and conscientiously e-mail comments and suggestions back to the teacher.

—They worry that their children are not learning what they will need to succeed at their next school.

—While a concern about the quality of their children's education is rarely the sole reason military members leave the service, the stress caused to a child by one-too-many moves, the special services not received when needed, or the prospect of an assignment at an installation where the schools have a poor reputation may be enough to convince a service member that it's time to leave the military. Some families become so frustrated with the problems involved in moving their children from school to school that the service members become "geographic bachelors." When they find a school which meets their children's needs, the service member leaves the family behind and moves on alone to the next assignment.

WHY IMPACT AID? THE FEDERAL RESPONSIBILITY

Military families understand that the Impact Aid program supports basic education services provided by their local school districts. They hold the government, and the citizens they have sworn to serve and protect, accountable for living up to their promise to provide a quality education for their children. The districts have accepted the responsibility to educate military children; the Federal government must provide the resources it has promised to support that education.

—The intent of the original Impact Aid legislation (Public Law 81–874) was "to provide financial assistance for those local educational agencies upon which the United States has placed financial burden." It originally provided an "in-lieu-of-tax" payment equal to the local per-pupil costs for students whose military parent both lived and worked on a federal installation (these students were designated A students) and one-half of the local per-pupil cost for students whose military parent worked on a federal installation but lived in the civilian community (B students).

—It costs roughly $6,000 to educate a child in the United States today.

But the current average Impact Aid payment for an A child is $2,000; the average payment for a B child $200, nowhere near the original intent or the cost to educate a child.

—The Federal government has acknowledged its responsibility to provide

Impact Aid, but the program has not been fully funded since 1970. Even with much-appreciated Department of Defense supplemental funding for the most heavily-impacted districts, Impact Aid does not cover many districts' basic needs.

NMFA particularly appreciates this subcommittee's support for continued Impact Aid funding for military children who live off the installation, the "military B students." Although military families living in the civilian community pay property taxes to help support local schools, this revenue is not enough to cover the costs of educating their children.

—States are increasingly providing a larger share of local districts' funding. Many military members pay no state tax on their military income. They also shop in military exchanges and commissaries, thus paying no sales tax. Under the provisions of the Soldiers' and Sailors' Relief Act, they are often exempt from paying personal property taxes on automobiles if they are on military orders away from their home state.

—A 300-unit apartment complex occupied by military families in Newport News, Virginia generates approximately $126,000 in property tax revenue for the county. The school district receives $17,000 in Impact Aid money for the 142 children who live in the complex (Military Bs). But, the local cost to educate these children in the local schools is $388,000. Local taxpayers absorb the deficit of $245,000 to educate these federally-connected students.

—The Bremerton (WA) School district receives about $334,000 per year in Impact Aid for the 1,500 military children and civilian shipyard workers at the Puget Sound Naval Shipyard. Most of these children live off the installation. Even though the children's families pay property taxes, the district must deal with the expenses of testing, placement in special programs, and remediation incurred by most districts dealing with large numbers of transient children. School accountability is difficult to measure in a district where the number of students moving in and out of some schools is equal to the total student population.

—Continued funding for B students is even more essential now that the Department of Defense is privatizing military family housing at many installations. In some cases, this action could result in the transfer of land to a private developer, turning Impact Aid A students into Bs. In other cases, the services are arranging for developers to build military housing in civilian communities rather than building homes on the installation. This could also result in more B students.

WHY IMPACT AID? QUALITY EDUCATION

A well-funded Impact Aid program enables districts serving large numbers of military children to approach the level of educational opportunity available in neighboring, non-impacted school districts even though they do not have access to the same kind of tax base.

—The Middletown (RI) School District puts its Impact Aid money into its general fund where it helps the district offset property taxes. About 40 percent of Middletown's students come from military families based at the Newport Naval Education and Training Center.

—The Central Kitsap School District serves military families from Bangor (WA) Submarine Base. Two installments of Impact Aid payments for heavily-impacted districts will enable the district to purchase 650 new Pentium computers. The computers will not only benefit students, but will speed record-keeping for teachers who are required to submit their grades and attendance electronically. Other Impact Aid funds will be used for building repairs and renovations.

—Impact Aid dollars are targeted to districts where the Federal responsibility is the greatest under the law. The dollars go directly to school districts with no strings attached. The local community, the people with the greatest stake in the quality of education in their schools, decides how Impact Aid funds will best serve the basic education needs of all students.

FIX THE SCHOOLHOUSE

For a newly-arrived family in a military community, the sight of a well-maintained, safe, child-friendly school building can calm many anxieties about their latest move. Unfortunately, too many military children must deal with those anxieties in a school facility that has seen better days.

—Many school districts educating military children have older buildings which are expensive to maintain and ill-equipped to handle technology or certain mandated programs such as special education. Approximately 30 percent of the enrollment in the North Chicago (IL) Community Unit School District #187 are military children whose parents are based at the Great Lakes Naval Training Center, the Navy's only recruit training center. The district does not have the

tax base to support its plan for constructing ne ighborhood schools which would serve its surging enrollment. Its superintendent states that "time on task, class size and educational programs are all impacted by limited space." The maintenance of the old buildings draws valuable resources away from the education needed by the district's children.

—Recent population growth in Harnett County, North Carolina was partially fueled by the down-sizing of some military bases which sent more families to near-by Fort Bragg. Because all of the 1,100 military children attending Harnett County schools live off the installation, the district receives only about $36,000 in Impact Aid. The installation has donated land for three schools, but the county needs to raise money for construction. Until new schools can be built, many children attend school in trailers. A parent described conditions in these trailers for a local news reporter: "It's hard to pay attention to education in the trailers. Heating and air conditioning units make so much noise that teachers turn them off. Then the heat or the cold distracts the kids. Bathroom breaks are lengthy trips to the main building—with no covering over the path from trailer to school if the weather is bad. During fire and tornado drills, the children crowd into the hallways, unable to find a sheltered area in the trailers."

—Finding funds to repair and update the buildings owned by the Department of Education on military installations is a burden for districts serving military children. Photos in Appendix A illustrate some of the maintenance needs at Fort Sam Houston's schools. The district has served military children well from these schools—both the Elementary and the High School have been recognized as Blue Ribbon Schools of Excellence by the U.S. Department of Education. The district has also found funds to build a Junior Reserve Officers Training Corps building and a Professional Development Center. It needs a new middle school but, as a co-terminus district with no tax base, it has a difficult time raising major construction funds.

—Randolph Independent School District (TX), serving Randolph Air Force Base also is experiencing over-crowding in its old Department of Education-owned buildings. Its middle school is currently housed in an annex to the high school and in portable classrooms. Middle schoolers use the bathroom and other facilities in the high school.

—Districts operating buildings owned by the Department of Education want to give children living on military installations the same quality of education offered to children living off the installation. When the Department of Education does not receive the funds needed to maintain or upgrade buildings, it must make choices which diminish the quality of education. A few years ago, the North Hanover (NJ) Township School District, which serves children on McGuire Air Force Base, requested funds from the Department of Education to add a library to one of the five Department of Education schools on McGuire. The superintendent stated that his request was refused by the Department because "libraries are not required in elementary schools."

STRENGTHENING THE PARTNERSHIP

Military children are everyone's children. The quality of education a military child receives in the Texas school she attends in 1st grade, for example, will affect the education she and her classmates receive in the California school she attends in 4th grade. Children whose schools are unable to provide the necessary educational services could easily fall behind their peers in other districts. Schools serving these children could face difficulties in maintaining accreditation as tough new standards are implemented in many states. A smooth transition into their next school, whether across the state or across the county, benefits military children, their new classmates and their communities.

—School districts serving military children recognize their interdependence and are increasing their communication with each other to ease the transition of military children in and out of different school systems. These districts are talking to each other about how the variety of state accountability tests might affect their transient populations and their own performance on those measures.

—Recognizing that service members view quality education as an important component of the Quality of Life of military families, the services have stepped up their efforts to establish partnership programs with local schools, provide better information to help ease families' transitions to new schools, and study the problems faced by military children as they move. They are implementing training for installation school liaison officers to improve communication with local

schools and provide an advocate for families unfamiliar with the school system's chain of command.

—School districts, military installations, and concerned educators, military leaders, Department of Defense civilians who supervise military family programs, and parents are working together to ease the transition of military children into new schools in a new organization. The Military

Child Education Coalition is a national, non-profit association dedicated to networking schools and military installations and "developing processes which address transition and other educational issues related to the milita ry child." The Coalition received its initial funding from the Killeen (TX) Independent Schools district, but now has a national membership representing all services. The Coalition is coordinating the third national conference on "Serving the Military Child," which will be held in June at Offutt Air Force Base, Nebraska.

To military parents, the partnerships between their schools and military installations are powerful indicators of the importance of quality education for military children. The joint efforts of school districts and military leaders through the Military Child Education Coalition and service initiatives spark hope that some of the anxieties about transferring from school to school will be eased for families. The educational focus of these efforts demonstrates the effectiveness of the Impact Aid program as a partner in providing a quality education for military children. When the Federal government fulfills its responsibility to provide funding for basic education to districts serving military children, the districts can concentrate on creating a high-quality educational program for all students. We urge you, the Members of this Subcommittee, to be active partners in the education of military children and fully fund Impact Aid.

PREPARED STATEMENT OF DAVID M. GIPP, PRESIDENT, UNITED TRIBES TECHNICAL COLLEGE

UNITED TRIBES TECHNICAL COLLEGE: MAKING A DIFFERENCE

Summary of Request. For thirty years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from the Great Plains and throughout the nation. An intertribally controlled educational institution,[1] UTTC was assisting Indian people in moving from public assistance to economic self-sufficiency long before the 1996 welfare reform act. Our placement rate in 1997 was 96 percent. Our request for fiscal year 1999 Department of Education funding for tribally controlled postsecondary vocational institutions as authorized under Carl Perkins Vocational and Applied Technology Act is $5 million, or $900,000 over the fiscal year 1999 enacted level.

This funding is essential to our survival as we receive no state-appropriated vocational education monies.

We also bring to your attention and support the funding recommendations of the American Indian Higher Education Consortium, of which we are a member.

THE ADMINISTRATION'S REQUEST

Section 117 of the Carl Perkins Vocational Education and Applied Technology Education Act Amendments of 1998 (Public Law 105–332) authorizes funding for tribally controlled postsecondary vocational technical institutions. Under this authority (and also under the prior version of the Perkins Act) funding is currently provided to UTTC and one other tribally controlled postsecondary vocational institution, the Crownpoint Institute of Technology. The Administration's fiscal year 2000 request is $4.1 million, the same as the fiscal year 1999 enacted level. There is a glitch in the newly reauthorized Perkins Act in that it caps funding for Tribally Controlled Postsecondary Vocational Institutions at $4 million instead of authorizing "such sums as may be necessary" in the out years as is the case for other vocational education programs. We believe this was inadvertent and ask for a technical correction to provide for "such sums as may be necessary" for fiscal year 2000 and the out years for Tribally Controlled Postsecondary Vocational and Technical Institutions.

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[1] The college is owned and operated by five federally-recognized tribes situated wholly or in part in North Dakota. These Tribes are the Spirit Lake Sioux Tribe, the Sisseton-Wahpeton Sioux Tribe, the Standing Rock Sioux Tribe, the Three Affiliated Tribes of the Fort Berthold Reservation, and the Turtle Mountain Band of Chippewa. Control of the institution is vested in a ten-member board of directors comprised of elected Tribal Chairpersons and Tribal council members.

UNITED TRIBES TECHNICAL COLLEGE: A UNIQUE INTER-TRIBAL EDUCATIONAL ORGANIZATION

United Tribes Technical College is the only inter-tribally controlled, campus-based, postsecondary vocational institution for Indian people. Our campus is the site of the Fort Lincoln Amy Post, an 110-acre area near Bismarck, North Dakota. We currently enroll 310 students from 36 tribes and 17 states. In addition, we serve 110 children in our pre-school programs and 115 children in our elementary school, bringing the population for whom we provide direct services to 535. In some years our students come from as many as 45 tribes.

EDUCATING STUDENTS AND PLACING THEM IN JOBS

We are proud of the education, skills and services provided by UTTC for our students and their families over the past thirty years. And we are proud that this education is taking placing in a tribal setting, where our students and their families can maintain and strengthen their tribal heritage. We have had a placement rate exceeding 80 percent sustained over the last 10 years, and in 1997 had a placement rate of 96 percent. This success is all the more gratifying in light of the background of our students, most of whom come from tribal areas where poverty and unemployment are the norm. A large proportion of our students are from the fourteen tribes in the Dakotas, where unemployment among Indian people is chronic. BIA Labor Force data reports the percentage of potential Indian labor force on and near reservations in the Aberdeen Area (ND, SD, Nebraska) who are jobless is 71 percent. Of those persons who are employed salaries are so low that 33 percent are living below the poverty guidelines.

UTTC COURSE OFFERINGS AND COORDINATION WITH OTHER EDUCATIONAL INSTITUTIONS

UTTC offers 8 Certificate and 13 Associate of Applied Science degree programs.[2] Entrepreneurship and new technology skills are being integrated into appropriate curricula. Recently we expanded our business program. And our newest program offering is a two-year degree program in injury prevention which was established in September of 1998. We are the first tribal college in the nation to have this course of study. The purpose of the course is to train students for injury prevention specialist jobs, and to try to change the culture of injury in Indian country. The program offers classes including Introduction to Injury Prevention, Prevent of Traffic-Related Injuries, and Prevention of Injuries Due to Violence.

The death rate among Indians due to injuries is 2.8 times that of the total U.S. population (Source: Indian Health Service fiscal year 1999 Budget Justification Book). Reducing the incidence of injuries in Indian country is an area of focus for both the IHS and the Surgeon General. We received assistance through the IHS to establish our Injury Prevention curricula.

All our programs are accredited through the North Central Association of Colleges and Schools at both the certificate and two-year degree granting levels. During the last re-accreditation process (1996), the NCACS authorized UTTC to begin developing curricula for four-year degrees.

UTTC has transfer and articulation agreements with other colleges so our graduates can transfer to four-year schools from areas including Licensed Practical Nursing, Criminal Justice, Business and Entrepreneurship and Health Instruction.

UTTC has been a member of the Interactive Video Network of North Dakota's colleges, universities and tribal colleges since 1994. This is expanding the educational opportunities for our students.

JOB TRAINING AND ECONOMIC DEVELOPMENT

UTTC is a designated Indian Minority Business Center serving Montana and the Dakotas. We also administer a Job Training Partnership Act program and an internship program with private employers. And, thanks to a grant from the Kellogg

[2] The following one-year certificates are offered: Office Technology; Automotive Service Technician; Construction Trades Technology with options in Carpentry, Electrical, Plumbing, and Welding; Early Childhood Education; Criminal Justice; Hospitality Management: Food & Beverage Specialization; Medical Secretary.; and Welding Technician.

The following two-year Associate of Applied Science (A.A.S.) degrees are offered: Arts/Marketing; Automotive Service Technology; Construction Trades Technology with options in Carpentry, Electrical, Plumbing and Welding; Criminal Justice; Early Childhood Education; Health Information Technology; Hospitality Management: Food & Beverage Specialization; Office Technology with emphasis in computer applications or accounting; Practical Nursing; Small Business Management; Welding Technology; Dietetic Technician, and Injury Prevention.

Foundation, we are assisting tribes and tribal members in the Aberdeen Area with rebuilding buffalo herds.

COORDINATION WITH STATE WELFARE-TO-WORK EFFORTS

UTTC is working in cooperation with the state of North Dakota on welfare reform. We are serving state-referred Temporary Assistance for Need Families (TANF) recipients who are able to participate in our Cooperative Education internship program with private employers. By attending UTTC, these TANF recipients can meet their work, training and volunteer requirements. And we are providing child care for 60 children of state-referred TANF recipients.

We take exception to the 12-month statutory limit on the length of time a TANF recipient can be enrolled in a vocational education course and still be eligible for TANF. This limits TANF recipients to taking one-year certificate courses at UTTC. Our experience shows that the students who graduate from a two-year, rather than a one-year, course have significantly higher earning power. Many of our students come to UTTC planning to take a one-year course, and then, finding themselves in a supportive environment and seeing the economic benefit of the longer course, decide to work for the two-year degree.

SERVING FAMILIES CONTRIBUTES TO EDUCATION AND JOB PLACEMENT

We believe that a primary reason for UTTC student success is that we serve the students' social, academic and cultural needs. Many of our students are the first generation in their family to attend college and for many it is their first experience in living away from home. Many students are on public assistance and many have families of their own. Some of our services are:

—Early childhood services for 110 children, ages 8 weeks to five years;
—The Theodore Jamerson Elementary School (grades K–8) serving 115 Indian students;
—A health clinic whose services include immunization, health education, eye and dental exams, and referrals to other health care providers;
—Family housing and dormitories for solo parents and for students without children;
—A local transportation system for students for school activities and necessary appointments e.g., (doctor appointments) outside the campus. Most UTTC students do not have cars.

UTTC SEEKS OTHER FUNDS

We are aggressive in seeking funding outside the Perkins Act for special needs. For example, we combined Department of Agriculture, Economic Development Administration and state Community Development Block Grant funds and replaced our aging water, sewer and gas systems in 1997.

Our elementary school received a competitive Department of Education grant for computer technology, and was one five Indian schools to receive this funding. We also received a Kellogg Foundation grant to develop buffalo management skills for the tribes and their members throughout the Aberdeen Area, as they attempt to rebuild herds of buffalo decimated more than 100 years ago.

The above mentioned grants are highly competitive, restrictive, one-time grants, and they cannot provide for day-to-day operations. We cannot survive without the basic operating funds which come through the Department of Education's tribally controlled postsecondary vocational institutions program.

CURRENT NEEDS

We certainly appreciate the $1 million increase provided by Congress in fiscal year 1999 for the tribally controlled postsecondary vocational program (from $3.1 million to $4.1 million). The increase was important, not only for the unmet needs of the current grantees, but because other institutions may become eligible for funding under this program. The fiscal year 1999 funds have not been allocated yet, and because this is a competitive program, we do not know yet how much our college will receive.

The operating and purchasing strength of our budget has diminished by some 20 percent since 1990. Utility costs are especially difficult. Electricity expenses have risen about 20 percent per unit and the per unit gas costs have increases approximately 113 percent during this decade. We have been able to partially offset utility rate increases by implementing stringent conservation measures such as improved weatherization and reductions in building temperatures. However, energy consump-

tion cannot be further reduced because of our location and the harsh winters in the northern plains.

While even a $5 million appropriation for the Tribally Controlled Postsecondary Vocational and Technical Institutions program would leave us with enormous needs, it would allow us to make improvements in key areas including course offerings, student services, and technology. Below are some of our financial needs of which we want you to be aware;

—*Housing*.—We need new and rehabilitated campus housing so that we can increase student enrollment. Many of our buildings are of historic importance. The College occupies the old Fort Lincoln Army Post, and many people visit our campus to see these buildings. Other than the more recently constructed skills center and the community center, UTTC's core facilities are 90 years old. Estimates for new facilities total over $12 million, according to a 1993 Department of Education report to Congress. Continuing a course of non-repair will ultimately prove more costly as the repairs will be greater. Fire and safety reports document our repair needs.

—*Salaries*.—We were able to provide a cost-of-living increase for our employees last year. However, our faculty still receive salaries that are lower than in any state college system. North Dakota salaries for higher education faculty are the lowest in the nation—but the average faculty salaries at UTTC are even lower than those in the North Dakota state system.[3]

—*Emergency repair*.—Our needs for emergency repair on both single and family student housing, instructional facilities and support facilities exceeds $100,000. This amount will obviously not cover major renovations or new facilities. Funding is also needed for maintenance and repair related to damaged caused by inclement weather, including blizzards and extremely low temperatures.

—*Technology*.—We need funding for updating our computers and hardware to maintain and increase our capabilities for distance learning programs for our campus-based students and students at other locations. We have been working with the Denver Indian Center to provide UTTC classes, via distance learning, to the Indian population in the Denver area. Thus far we have three classes on-line and are expecting to begin operations soon.

—*Course Offerings/Student Services*.—We would like to change some of our courses to better meet new market demands. For example, we want to expand the allied health professions program. We also need to expand our diagnostic capabilities in tribal-specific areas and also in the areas of literacy and math-science background. This would allow us to improve student remediation services. Finally, we want to make improvements in our student follow up, career development, and job market research efforts.

AMERICAN INDIAN HIGHER EDUCATION CONSORTIA (AIHEC) TESTIMONY

We support the testimony submitted to this Subcommittee by the American Indian higher Education Consortium. We are one of the 32 tribal college members of AIHEC. Tribal colleges are now (since the 1998 Higher Education Act Amendments) authorized to receive $10 million under the Title III (section 316) Institutional Development program, and we urge that this funding be appropriated. We also support the AIHEC requests for the Indian student teacher initiative and the Indian Education Act adult education program. The tribally-based colleges, although funded at much lower levels than other colleges, are making a positive difference for their students and their communities. They are an impressive example of tribal governments approaching issues of economic development, education, and preservation of tribal communities and cultures through the creation of culturally-based higher education institutions.

Thank you for your consideration of our request. We need your assistance to ensure that the unique educational opportunities offered by United Tribes Technical College will be available for what we hope will be an increasing number of Indian and Alaska Native students and their families next year and in the future.

PREPARED STATEMENT OF PRESTON MCCABE, PRESIDENT, PINON CHAPTER AND PINON COMMUNITY SCHOOL BOARD

Mr. Chairman and Members of the Committee: My name is Preston McCabe. I am president of the Pinon Chapter of the Navajo Nation and president of the Pinon

[3] Source: Integrated Postsecondary Education Data Systems (IPEDS) Report of the U.S. Bureau of the Census and the Department of Education Office of Education Statistics.

Community School Board. I am presenting testimony in support of the Head Start and Bilingual Education programs.

Our community of 11,000 is comprised of Pinon and seven other Chapters of the Navajo Nation. While we have made much progress in recent years, many Indian children remain at the bottom of the economic and educational ladder. In 1990, more than one-third of all Indian children ages 5 to 17 were living below the poverty level. Furthermore, the high school completion rate for Indians ages 20 to 24 is 12.5 percent below the national average.

HEAD START

We must do more to help our children meet challenging educational standards that will allow them to compete in tomorrow's economy. There is compelling evidence that high-quality early childhood education programs is one way to achieve this goal. Therefore, we urge the Subcommittee to the following actions with respect to Head Start:

—Fully fund the Administration's fiscal year 2000 budget request of $5.3 billion for the Head Start program;
—Prioritize the construction of badly-needed tribal Head Start facilities; and
—Encourage the Department of Health and Human Services (HHS) to allow tribal organizations to administer Head Start programs under Public Law 93–638 self-determination contracts.

Budget request would allow us to serve more eligible children

At the Pinon Community School, children who have attended Head Start are more ready to learn. Unfortunately, the current funding level does not allow us to serve all of our Head Start-eligible children. The Head Start program serves 20 children, plus another 30 children though home-based instruction. That said, at least 391 children are eligible for comprehensive Head Start services, based—but we lack the funding and facilities to expand our program.

That is why we strongly support the Administration's long-range goal of increasing Head Start enrollment to one million. If the Subcommittee fully funds the Administration's fiscal year 1999 budget request of $5.3 billion, another 42,000 children will reap the benefits of Head Start and we will be one step closer to reaching this important goal.

We also urge the Subcommittee to fully fund the $420 million budget request for the Early Head Start program, which will support approximately 45,000 infants and toddlers—and their families.

Replacement facility construction should be prioritized

Without funding to build new—and safe—facilities, the goal of increasing Head Start enrollment to one million will be meaningless to Pinon. Currently, our Head Start program is located in a 20-year-old classroom that only accommodates 20 students. In order to expand services to the 391 children who are eligible for Head Start, we will need an additional building.

Therefore, we ask you to allocate a specific portion of the fiscal year 2000 Head Start appropriation for facility needs.

Let tribes administer local head start programs

Section 102 of the Indian Self-Determination Act (Public Law 93–638) directs the Secretary of Health and Human Services (HHS) to contract with tribes to operate federally-funded programs for their members.

The Pinon Community School Board has successfully contracted education programs since 1988 and has continually improved student services during this time period. As such, the Board believes that administering a tribal Head Start program through a self-determination contract would be beneficial. It would decrease the amount of federal bureaucracy that we deal with by allowing us to receive all of our funds directly from Head Start using one funding document and would let us to run our local programs to meet local needs. Currently, we receive our funding from the Chinle Agency, which in turn receives the funding through the Navajo Nation, Division of Dine Education, Department of Head Start.

We request that you include fiscal year 2000 report language that would encourage the Secretary to work with tribes to fully implement the Indian Self-Determination Act so that tribal organizations may contract Head Start.

BILINGUAL EDUCATION

We request that the Subcommittee provide the amount requested for Bilingual and Immigrant Education, $415 million and provide funding for the dissemination of instruction materials in Native languages.

In 1994, Congress authorized the Secretary of Education to provide grants to develop, publish, and disseminate instructional materials in Indian, Native Hawaiian, Pacific Islander, and outlying territories languages. This program has never been funded. Therefore, we urge the Subcommittee to include report language instructing the Secretary to allocate fiscal year 2000 funding for this purpose.

At Pinon, 86 of our are considered to have Limited English Proficiency. It is our goal to provide these children with comprehensive bilingual education so that they can learn English and meet challenging academic standards, all the while maintaining a knowledge of and respect for their native language.

To meet this goal, it is critical that we have funding to train personnel and to develop innovative bilingual education programs at the local level.

CONCLUSION

Thank you for your consideration of our concerns and comments. The Pinon Community School appreciates the funding that the Subcommittee has provided in the past to Head Start and Bilingual Education, and we look forward to your continued support.

PREPARED STATEMENT OF THE CITY OF MIAMI BEACH, FL

Mr Chairman and Members of the subcommittee, the City of Miami Beach, Florida appreciates the opportunity to present testimony on two important initiatives for which we are seeking Federal assistance.

BISCAYNE ELEMENTARY/21ST CENTURY LEARNING CENTER

Biscayne Elementary is an ideal site for a 21st Century Learning Center for multiple reasons. Greatest among these is the community which Biscayne Elementary serves. The neighborhoods surrounding Biscayne Elementary are home to the most economically and socially disadvantaged residents of Miami Beach. Poverty, distressed families, social isolation and cultural/ethnic diversity are all obstacles in the delivery of much-needed services. Biscayne Elementary, the geographic and social center of North Beach, is housed within a building built decades ago for a population considerably smaller than it now must house.

In addition to overcrowding and a poor community base, Biscayne Elementary is in dire need of expansion and rehabilitation to best serve the educational needs of its current student enrollment. Class overcrowding and the absence of technology in the classroom experience result in a lifetime disadvantage for the school s students. More importantly, the coupling of these deficiencies with the social obstacles in the surrounding community create an almost overwhelming challenge for area youth.

The North Beach area has significant problems including gangs, drugs, high crime, unemployment/underemployment, poverty, a concentration of multi-unit rental housing, poor community cohesion and one of the most culturally diverse populations in the county. While the City of Miami Beach has begun to leverage a variety of resources for the area including law enforcement and public services, a strong educational foundation is central to the community s financial and social progress.

Biscayne Elementary is in dire need of an infusion of resources including a long-overdue rehabilitation of the existing building and an expansion to add additional classrooms as a means of alleviating class overcrowding. In addition, technology must be integrated into the classroom in response to the needs of the marketplace. More so, the social needs of the surrounding community demand that Biscayne Elementary become a full-service school center with access to much-needed social services, before and aftercare programming, and an expansion of Head Start and prekindergarten programs for working families residing in nearby homes and rental housing.

The upgrade of Biscayne Elementary to a full-service, 21st Century Learning Center will provide the community with a solid foundation upon which to build social and economic parity with the rest of the City. The provision of needed services within the neighborhood will provide area stakeholders a means by which to access economic and social opportunities for betterment. More importantly, a strong tie with the area's school will foster greater community cohesion and provide a basis upon which to address other social and economic concerns.

MIAMI BEACH REGIONAL LIBRARY AND CULTURAL CAMPUS

The City of Miami Beach has made tremendous strides in the recent past to create a uniquely dynamic, exciting, culturally rich and diverse community. What the

community still requires is a civic and cultural heart, a place of high ideals that will appeal to all the people who make Miami Beach their home, as well as the many tourists who visit every year. The City has designed, and is in the process of developing, a cultural and arts campus centered on Collins Park which will create this heart.

This Cultural Campus is centered around Collins Park which goes from Collins Avenue, Florida Highway A1A, to the Atlantic Ocean. Across Collins Avenue from Collins Park is the existing Library with the Bass Museum behind it. The Bass Museum is now being expanded and will remain the focus point of the completed Cultural Campus. Across 22nd Street from the Bass Museum, a new home for the Miami City Ballet is now under construction. The new Regional Library, which will serve the entire City of Miami Beach, will be constructed across Liberty Avenue from the Miami City Ballet and northeast of the existing library. The Bass Museum, the Miami City Ballet, the Regional Library, Collins Park, and the associated streetscapes compose the Cultural Campus which is located between 21st Street and 23rd Street and from the Atlantic Ocean to Park Ave.

Even though the library will be owned by the City of Miami Beach, the library will be managed by the Miami-Dade Public Library System. Being a part of the Miami-Dade System not only permits patrons to use the new facilities at this library, should a patron desire a book that is not in the library, the book can be sent to this library from one of the other 29 branches or the main library in the Miami-Dade System. The book should be available the next day.

In addition to the Regional Library, there are two small branch libraries in the City of Miami Beach. The regional library supports the two smaller libraries with in-depth resources not available at smaller libraries.

The Regional Library will provide a serene atmosphere for studying, research, or relaxing, in the large area for adult and young adult collection. These areas also have access to the cafe and the court yard which has a pergola, fountain and specimen tree. Seats will be available in the court yard for enjoying refreshments from the cafe.

When the library is completed there will be telecommunication outlets for 60 computers. However during construction of the building, facilities will be installed to increase the number to 100 telecommunication stations.

The second floor will be for use primarily by children. With a large Children's Library as large as the Children's Room at the Main Library in Miami. The Children's Library will have a Children's Desk, Toddler Area, Picture Books Room, special area for kid's displays, and special rooms for story telling, arts and crafts and a work room. An office is also available for the Manager of the Children's section.

An auditorium is also available for special meetings or presentations. The auditorium is at the front of the library and will be available beyond the normal operating hours of the library.

The estimated cost of the library is $11,500,000 plus the cost of the land which is estimated to be $3,760,000. The City respectfully requests funding in the amount of $3.5 million to assist with these much needed improvements

TARGETED EMPLOYMENT INITIATIVE

The arts and entertainment and environmental sciences industries have experienced explosive growth in South Florida. The higher-than-average wages paid and diversity of employment within these industries compliment the South Florida market.

As these industries grow so, too, does the need for skilled labor to fill the employment demand. In the case of the arts and entertainment industry, a variety of labor is needed including: light and sound engineering, design, pre- and post-production, promotions, craft services, transportation, logistics management, etc. The environmental sciences industry demands skilled labor such as: biological engineering, waste management services, environmental sciences, water management, etc. In order to meet these demands for skilled labor, a concerted effort to train workers directly from our schools is needed.

While South Florida has a variety of magnet schools for the performing arts, there are only two schools in the district with curriculum-supported programs for the non-performing employment opportunities within the industry: Miami Beach Senior High School and Miami Northwestern Senior High. Of these two, the City of Miami Beach offers a stronger infrastructure including year-round good weather, multi-faceted shooting locales, field offices for most of the art industries major corporations, and an international stream of tourists and cultural consumers.

The environmental sciences industry will continue to grow as efforts are underway to manage South Florida s seemingly endless man-made canals and the clean-

up of the long-neglected ,and economically essential, Miami River. The strains placed on our environment can jeopardize the area s tourism industry unless proactive steps are taken to curb pollution and environmental neglect and abuse.

Miami Beach would like to meet the labor demands of these two burgeoning industries. In conjunction with local public schools, the City of Miami Beach would like to create paid internships structured within a school-to-work format to prepare youths to meet the labor demands created by the arts and entertainment and environmental sciences industries, respectively. Our growing population, geographic location (as it relates to the global marketplace), and inviting economic climate provide the perfect environment in which to foster the growth of these two industries. The need to provide capable and plentiful labor is central to maintaining these industries once they have a foothold in the area.

The fast-changing global marketplace demands that economic resources be channeled quickly as the market s needs change. It is imperative that a quick response be provided to both the arts and entertainment and environmental sciences industries. More importantly, the universal nature of these industries create a demand beyond the traditional boundaries of immediate geography. An investment in the labor pool to support these industries is an investment in the long-term economic health of South Florida.

Thank you for your consideration of these requests which are very important to the residents of Miami Beach, as well as the surrounding communities.

PREPARD STATEMENT OF M.H. BAHREINI

HOWARD UNIVERSITY'S WASTING OF TAXPAYERS' MONEY

Attached please find copies of the testimonies that I have submitted to the Sub-Committee on Labor, Health & Human Services, and Education of the Committee on Appropriations, United States House of Representative, regarding appropriations for Howard University, a private institution that receives millions of dollars of taxpayers money every year for reasons that many believe no longer exist.

My last year's testimony was submitted on behalf of hundreds of Howard University students who had called for the elimination of Howard University's unpopular and under-enrolled graduate programs. Since that testimony didn't raise any concern for any member of the Congress to call for an investigation, I am submitting another testimony this year.

I worked as a faculty at the Howard University for eight years (1989–1997.) Every year I saw millions of dollars of taxpayers' money being wasted at Howard University for paying high salaries to administrators and for payment to the faculty for offering under-enrolled (one to three students) classes. When its former President left the University, Washington Post reported that he had been the highest paid of all university presidents in the Nation that year!

Attached to my current testimony please find a few pages of the "Instructor's Report of Grades" that are submitted as evidence to show that courses have been offered by full-time faculty to only two students. The professors of these "three-hours-a-week" courses have been paid full-time salary to offer two or three of such courses (i.e. one faculty teaching two students 6 to 9 hours a week!) every semester!

I respectfully ask every member of the Congress that is it fair that every year millions of dollars of the earnings of the hardworking taxpayers of this country be transferred to a private institution without any independent investigation on how that money is spent? Is Howard University still delivering the services that it was once "historically" expected to deliver?

HONORABLE JOHN EDWARD PORTER, III, CHAIRMAN, SUB-COMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, AND EDUCATION COMMITTEE ON APPROPRIATIONS, UNITED STATES HOUSE OF REPRESENTATIVE—APRIL 15, 1999

HOWARD UNIVERSITY'S WASTING OF STUDENTS' AND TAXPAYERS' MONEY

I submitted a testimony last year as a concerned citizen and on behalf of hundreds of Howard University students who had called for the elimination of Howard University's unwanted graduate Programs. Apparently, my testimony didn't raise any concern for any member of the Congress last year, and the business is still "as usual" at the Howard University.

I worked as a Lecturer at Howard University for eight years (1989–1997.) Every year I saw millions of dollars of taxpayers' money being wasted at Howard University for paying high salaries to administrators and for payment to the faculty for offering unwanted classes. As a concerned citizen, I intend to continue to submit a

testimony every year until a responsible member of the Congress calls for an investigation.

Attached to this letter please find a few pages of the attachments to my last years' testimony showing samples of the "Instructor's Report of Grades" for courses that have been offered by full-time faculty to only two students at one of the graduate programs at the Howard University .

As long as Howard University is receiving millions of dollars of taxpayers' money every year, I believe it is the responsibility of the Committee on Appropriations and the Congress to end corruption at that private institution.

HON. JOHN EDWARD PORTER, III, CHAIRMAN, SUB-COMMITTEE ON LABOR, HEALTH & HUMAN SERVICES, AND EDUCATION, COMMITTEE ON APPROPRIATIONS UNITED STATES HOUSE OF REPRESENTATIVE—MARCH 25, 1998

HOWARD UNIVERSITY'S WASTING OF STUDENTS' AND TAXPAYERS' MONEY

I am writing this testimony as a concerned citizen and on behalf of hundreds of Howard University students who have signed the attached petition to Mr. Swygert, the President of that University, calling for the elimination of Howard's unwanted graduate programs.

I hold a Ph.D. (1986) degree in Economics from The American University, Washington, D.C.. I worked as a Lecturer at Howard University for eight years (1989–1997.) Every year I saw millions of dollars of taxpayers' money being wasted at Howard.

A major form of wasting money by Howard is to offer graduate courses to three or less students! In many of these classes no effective instruction is actually taking place.

If we believe in a free market system, we should respect "consumer sovereignty" and "demand side" of the education market. This means that Howard should shut down its graduate programs that do not have enough customers.

As a taxpayer, I believe, that it is the responsibility of the Department of Education and the Committee on Appropriations to have Howard University work for millions of dollars that it receives every year. Please consider the following suggestions for achieving this goal:

1. As long as Howard is receiving taxpayers' money, it shouldn't be allowed to offer a course for less than 7 students.

2. Howard should receive its money indirectly through the area's Departments of Employment Services. For every one million dollars received, Howard should be expected to train at least 250 job seekers in the fields demanded by the current job market.

PREPARED STATEMENT OF STEPHEN A. JANGER, PRESIDENT, CLOSE UP FOUNDATION

Mr. Chairman, distinguished members of the Subcommittee my name is Stephen A. Janger and I am president of the Close Up Foundation. I appreciate the opportunity to submit testimony in support of the Allen J. Ellender Fellowship Program administered by the Close Up Foundation. Before beginning, I want to express, on behalf of everyone at the Foundation, our deep appreciation for the Subcommittee's past support. We are very much aware that tens of thousands of economically disadvantaged students would not have had this important civic learning opportunity without the Allen J. Ellender Fellowship Program.

As we approach the new millennium, in our field of civic education, we are faced with a troubling and dangerous trend of increasing voter disengagement and distrust, particularly among young people. Our American democracy approaches the new century with a diminishing key component of civic health—informed citizen participants. This trend mirrors the mood in the country at the time of Close Up's establishment in 1970. As we have testified before, the disenchantment of America's young people with their government was a principal reason behind the establishment of the Close Up Foundation. The addition of Ellender Fellowships as a part of Close Up's work has helped to ensure that America's diversity, one of its proudest and strongest assets, could be mirrored in our programs.

The findings of a fall 1997 UCLA survey of college freshmen's attitudes toward the importance of civic awareness are reinforced in a recently released study sponsored by the National Association of Secretaries of State (NASS). The NASS project entitled, New Millennium Project, Part 1, American Youth Attitudes on Politics, Citizenship, Government and Voting, was initiated in response to the 1996 presidential election voter turnout of 49 percent, the lowest voter turnout in 72 years, and the even lower 36 percent turnout in the 1998 midterm elections. As dismal as

those results are, the 1998 nationwide turnout for 18 to 24 year-olds of 20 percent was even more disturbing.

These findings are even more troubling when you realize that in 1972, the first year 18 year olds were allowed to vote, 50 percent of 18 to 24 year olds went to the polls. To try to understand this decline, the NASS committed to conduct a two part project to help identify strategies to reconnect American youth to the democratic process. Their recently released report completes the first part of the project and identifies the declining trends and some of the reasons underlying them. The report also outlines some strategies for reversing the trends.

There are currently 70.2 million American young people under age 18, the largest such segment of young people in the country's history. Engaging them in the participation of their own governance, is a challenge critical to the survival of American democracy. To briefly summarize the report's findings: the vast majority of America's youth (72 percent) do not feel it is their civic duty or responsibility to vote; by a margin of 64 to 35 percent, young people believe that "government is run by a few big interests looking out for themselves;" 58 percent feel "You can't trust politicians . . . ;" and, 55 percent agree that institutions (schools) do not do a good job giving students the information they need to vote.

Recently, Close Up conducted two surveys of student attitudes in the St. Paul/Minneapolis, Minnesota area and in the Miami, Florida area on civic responsibility at the community and national levels. The results of our two surveys unfortunately support the findings of the NASS study. Although our students are younger, primarily high school juniors and seniors, they share the sentiments of the 18 to 24 year-olds in the NASS study. They indicate their disengagement in their lack of desire to run for an elected office or pursue a public service career, and their distrust of national politics is reflected in most students feeling that if they had any influence at all it would be at the local level. The students also mirrored their older peers belief that the media strongly affects their views of government and government officials.

A major concern about this generation of 70.2 million young people is reaching them early enough in their education to create a positive attitude about their civic responsibilities to community and country. The NASS report suggests that we develop "creative and participatory solutions" if any real change is to occur. Developing innovative ways to reach and engage young people in civic education has been Close Up's mission during our more than twenty-eight years of experience. Hands-on participation has been the principal thrust of Close Up's experiential civic education programs from the beginning.

This experiential education focus continues to bear fruit. Participants throughout the country indicate that their Close Up program experience motivated them to become involved in public service and the political process. In our fledgling alumni program, we have identified eighty-seven Congressional staff members as former Close Up participants. To meet Congressional staff who tell us that Close Up is the reason they became interested in public service is a source of great pride to all of us at Close Up.

Another area of concern is the media's role in opinion formulation and the presentation of practical and balanced information to America's young people. As indicated earlier, young people in our surveys noted that the media strongly influenced their views of government. The NASS study suggests the media include more positive stories that highlight the relevance of political issues. While the media can play an important educational role, that role must be supplemented and balanced by more direct, participatory learning experiences about our government and elected officials. The NASS study and Close Up's surveys also found that a significant number of young people had very negative opinions of politicians and questioned their commitment to those they represent. Again, our experience underscores the importance of providing young people with the opportunity to meet and talk with their elected representatives as a way to counter misperceptions and create a healthier and more complete understanding of the democratic process.

Close Up has worked hard to be an effective antidote for this problem of showing "contempt before examination." Through presenting the realities of public service, the genuine commitment of elected officials, and the extraordinary difficulties of balancing the varied interests involved in the formulation of public policy, we have helped debunk the superficial and often negative impressions most students bring to Washington.

The NASS study found most young people did not believe they occupy an efficacious position in the American political structure. Fundamental to Close Up's Washington program is the promotion of student self-esteem and an awareness that each person can make a difference. Because young people feel disconnected from the political process, their feelings in large measure are reflected in their ambivalence

about voting. Because they don't vote, candidates are reluctant to expend campaign resources on this perceived non-voting group; thus, it becomes a classic "chicken and egg" problem.

Again, Close Up tries to break down these barriers. A key component of the Close Up week in Washington is the Capitol Hill day. On this day, Close Up participants have an opportunity to view Congressional committees at work, to watch House and Senate floor action, and, most importantly, to meet with their elected representatives or their staffs. Over and over, participants tell us what a profound change in attitude they experience after meeting with their Representative or Senator. They appreciate face-to-face meetings with questions and answers. These "simple" meetings do more than any textbook, lecture, or news report could ever hope to accomplish in connecting students to their elected representatives and instilling in them a feeling of belonging to the system and a receptivity to the whole idea of civic responsibility.

In both the NASS study and the Close Up surveys, young people felt that schools were not doing enough to teach them about citizenship and to motivate them to vote. The NASS study states flatly that, "Civic and political education should be a high priority in our schools. Our educators should make every effort not only to encourage students, but also to teach them how to be effective citizens." Again, since its establishment, Close Up has been a leader in answering this call through our teacher professional development program. This program is run concurrent with, but apart from, the student program. Teachers accompanying their students to Washington participate in this special program that presents them with new ideas and teaching methodologies. This program also promotes interaction with their peers. They swap teaching strategies and ideas that have worked in their classrooms. This inspiring exchange of ideas and teaching methods, this experiential "civic education teaching laboratory," simply cannot be equaled by the textbook alone. It is food for renewal and our teachers tells us that they return to their schools renewed and reinvigorated.

For little expenditure of federal dollars, the Close Up teacher program sends hundreds of renewed teachers home each year to teach civic education to all of the students in their classes, not just those who came to Washington. Additionally, many of these teachers are from schools that are considered "at-risk," or with large pockets of students most in need of assistance and/or motivation.

Thus, Ellender Fellowships create an impressive multiplier use of federal funds. The Ellender Fellowships are utilized by the teachers as "seed" funding to stimulate local interest and participation in the Close Up Washington program. For example, teachers often divide a full fellowship among several deserving students who meet the income eligibility requirement. These students, in turn, demonstrate their desire to participate in the program through local fundraising activities—often for an entire year and with considerable community support to supplement the fellowship portion. The Ellender Fellowship recipients are often the core around which teachers build the Washington High School program and the local and state government study programs, where again the creative leadership of the teachers is indispensable.

With the obvious contributions Close Up continues to make toward helping to alleviate a national problem of civic apathy and distrust, it is difficult to understand why the budget office in the Department of Education (DEd) continues to include erroneous and outdated information in their Congressional budget justifications. This year, the DEd again cited a 1996 report submitted to the House Appropriations Labor-HHS Subcommittee as a justification for not funding the Ellender Fellowship program. In that report, the Foundation renewed its commitment to continue its vigorous efforts to raise funds from the private sector. Accompanying the commitment, however, was an explanation of the difficulties associated with fundraising in the private sector. We also discussed in some detail the realistic limitations that we faced in the creation of our alumni program.

As we reported we would, we have undertaken the creation of an alumni program and it has been a source of great satisfaction as we get reacquainted with former participants who show enthusiasm for maintaining a connection. As we surmised they would be, however, the financial contributions from alumni have been very limited. Given the demographic characteristics of the individuals who make up our alumni base, our expectations for major financial support were very limited. We first had to find our alums and donor acquisition through direct marking/direct mail strategy is expensive and lengthy. Only recently have we begun to receive responses to our initial correspondence. Additionally, the age of the great majority of Close Up Foundation alumni is several years below that of the "typical" direct marketing donor, which is usually in the 50 to 55 plus range. The oldest of our alumni are just now in their mid-to-late forties (most are younger) and because of the passage

of time since their participation, they are the most difficult to locate and reach with any information. Also, the Foundation experienced its largest growth from the mid-eighties on. Most of our alumni are at the beginning of their professional careers and experiencing financial demands of their own personal and career pursuits. We will, of course, continue our determined effort to generate alumni donations, but it is a long and cultivating process which will not supplement the need for federal funds.

We are extremely proud of the fact that in June, we will celebrate the milestone of our 500,000th Washington program participant. We are equally proud that approximately 30 percent of those participants are from minority and underserved student populations. No other civic education organization can make these claims. This success is the result of a mission from which we have never deviated—a commitment to always try to reach students who need this experience the most.

Mr. Chairman, the Ellender Fellowship program is critical to Close Up's work of contributing to a more civil society—of creating a better understanding of and involvement in our democratic process. The Ellender Fellowships allow Close Up to reach students who are distanced from the political process by financial, geographic and cultural barriers. These students deserve every opportunity to become inspired about their country. Without the Ellender Fellowships, so many students each year will be denied the opportunity afforded to their more affluent peers.

We are grateful for the long-standing belief and support of this Subcommittee and the Congress. Your support of the Ellender Fellowships has been a great equalizer in the lives of tens of thousands of underserved students and, in today's climate of apathy and disaffection, your support is more important than ever.

Thank you for your consideration of our request.

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

INTRODUCTION

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 31 American Indian Tribal Colleges, which comprise the American Indian Higher Education Consortium (AIHEC), we thank you for the opportunity to share our fiscal year 2000 funding requests for programs within the Education and Health and Human Services Departments.

Under the Education Department programs, we have four specific funding requests:

Higher Education Act programs.—A newly-authorized section under Title III Part A Section 316, specifically supports Tribal Colleges, and we request that this section be fully funded at the authorized level of $10 million. In addition, under Title IV, we support the President's Budget request for fiscal year 2000 funding of the Pell Grant Program.

Perkins Act.—The Tribally-Controlled Postsecondary Vocational Institutions program (section 117) should be funded at no less than $4.1 million; and other Vocational and Adult Education programs should be funded at the levels requested in the President's fiscal year 2000 Budget. Funding under the Carl D. Perkins Vocational and Technical Education Act (set-aside for Indian and Hawaiian Natives) should be funded at no less than the fiscal year 1999 funding level.

Partnerships for Teacher Preparation.—This $10 million program, funded through the Office of Elementary and Secondary Education, Office of Indian Education, was proposed in the President's fiscal year 2000 Budget and would create a new and vibrant American Indian Corps of Teachers (AICT). We request that the funding for this program be specifically directed to the Tribal Colleges and we further request that Congress support the full $10 million for this program.

Greater Support of Title IX of Improving America's Schools Act.—This title supports adult education programs for American Indians that are offered by state and local education agencies, and by Indian tribes, institutions, and agencies. This section has not been funded since fiscal year 1995, yet Tribal Colleges need this funding to support the increasing number of adult education classes they provide to their communities. We request that this program be funded at a minimum of $5 million.

Under the Department of Health and Human Services programs, we request Congress recommend a $3 million level of funding for the Tribal College Early Childhood Initiative. This new initiative is funded through a Head Start discretionary grant program for fiscal year 1999.

Mr. Chairman, this statement will cover two topics: First, it will provide some background on the Tribal Colleges and second, it will provide justifications for the above funding requests.

BACKGROUND ON TRIBAL COLLEGES

The dismal statistics concerning the American Indian experience in education brought tribal leaders to the realization that only through local, culturally-based education could many American Indians succeed in higher education and help bring desperately needed economic development to the reservations. The Tribal College movement began more than 30 years ago as a very sound and well thought-out solution to this challenge. In the late 1960s and early 1970s, the first Tribal Colleges were chartered on remote reservations by their respective tribal governments, to be governed by boards of local tribal people. These early colleges were started with little money and a lot of determination, in abandoned and even condemned government buildings and old trailers, using three-legged desks, wood crates for shelves and typewriters with missing keys. In 1972, the first six fledgling tribally-controlled institutions came together to form the American Indian Higher Education Consortium. Today, AIHEC is a cooperatively sponsored effort and integral support network for 31 member institutions in the United States and one institution in Canada.

Tribal Colleges now serve more than 25,000 students each year, offering primarily two-year degrees, with some colleges offering four-year and graduate degrees. Together, the colleges represent the most significant development in American Indian education history, promoting achievement among students who may otherwise never know educational success. All of the Tribal Colleges are fully accredited, with the exception of the three institutions that are accreditation candidates.

Despite our successes, Tribal Colleges remain the most poorly funded institutions of higher education in this country, and although conditions at some have improved substantially, many of the colleges still operate in trailers, cast-off buildings and facilities with crumbling foundations, faulty wiring and leaking roofs. Our core funding, which is authorized under the Tribally-Controlled College or University Assistance Act of 1978 and funded through the Department of Interior appropriations bill, remains grossly inadequate. In fact, the Tribal Colleges' fiscal year 1999 appropriation of $2,964 per Indian student is dramatically less than the average per student revenue of mainstream two-year institutions and falls far short of the authorized funding level of $6,000 per Indian student. Despite an increase in our appropriation of $1.4 million in fiscal year 1999, due to the addition of another Tribal College and a 7 percent increase in enrollment, the Tribal Colleges are receiving $53 less per Indian Student for this budget year.

In addition to providing academic, vocational, and technical programs similar to those at mainstream institutions and cultural language and history courses unique to American Indian tribes, Tribal Colleges provide services above and beyond those provided by most other post-secondary institutions. Almost all Tribal Colleges provide GED, basic remediation, and other college preparatory courses. We have done this because our missions require that we help move American Indian people toward self-sufficiency and help make American Indians productive, tax-paying members of American society.

JUSTIFICATIONS

Higher Education Act requests.—The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the nation's Tribal Colleges (Section 316). The Aid for Institutional Development programs, commonly known as the Title III programs, support minority institutions and other institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. Tribal Colleges clearly fit this definition. Tribal Colleges are among the most poorly funded institutions in America; yet they serve some of the most impoverished areas of the country, bringing access to quality higher education programs targeted at the specific needs of their Indian students and communities. With the reauthorization of the Higher Education Act in 1998, Tribal Colleges finally joined Historically Black Colleges and Universities (HBCUs) and Hispanic Serving Institutions (HSIs) in receiving a well deserved set-aside within the Title III programs. Congress recognized that these institutions are young, struggling, and most in need of aid for development by authorizing a separate section at $10 million. Section 316 is subject to the two-year wait-out period that is required under general Title III Part A. This wait-out period was enacted to help ensure that Title III funding reached the maximum number of students and institutions. Due to the small number of Tribal Colleges, and their overwhelming developmental needs, the intended goal of the two-year wait-out period would be best achieved by exempting section 316 from this provision. Therefore, today, we request your support through the addition of report language that would address this oversight and exempt section 316 from the two-year wait-out period, and your support for the full funding of this new section for Tribal Colleges.

Tribal Colleges reached their peak level of participation in Title III in 1991, with 14 institutions receiving funds under this competitive program. Tribal College participation has never returned to the high water mark of 1991, largely due to the broadening of eligibility criteria for Part A. Currently, only eight Tribal Colleges are participating in the program. When accessed, the Title III program has been extremely important in bringing support in areas such as faculty and curriculum development, student services, and critical community-building programs. We urge the Subcommittee to fully fund this necessary section.

Under Title IV, we support the increased funding level in the President's fiscal year 2000 Budget for the Pell Grant program. The importance of Pell Grants to our students cannot be overstated. Education Department figures show that half of all Tribal College students receive Pell grants, primarily because student income levels are so low, and our students have less access to other sources of aid than students at mainstream institutions. The inadequate funding Tribal Colleges receive from the Federal government has forced most of the colleges into a position of increasing reliance on tuition for institutional sustainability. As a result, tuition levels at Tribal Colleges are as much as 30 percent higher than the average for mainstream public community colleges—in 1996–97, the average tuition at a Tribal College was $1,507, compared with a national average of $1,283 at community colleges.

Most Tribal Colleges are too young and too poor to have established institutional aid programs, and our students receive virtually no aid from the states, according to a recent study from the Institute for Higher Education Policy. Within the Tribal College system, Pell grants are doing exactly what they were intended to do: they are serving the needs of the lowest income students by helping people gain access to higher education and become active, productive members of the workforce. We urge you to support and expand upon this valuable program.

Perkins Vocational Education Act.—Section 117 (the TriballyControlled Postsecondary Vocational Institutions section) of the Carl D. Perkins Vocational and Technical Education Act provides core funding for two of our member institutions, United Tribes Technical College in Bismarck, North Dakota and Crownpoint Institute of Technology in Crownpoint, New Mexico and should be funded at no less than $4.1 million. In addition, funding for the set-aside for Indian and Hawaiian Natives under the Perkins Act should be funded at no less than the fiscal year 1999 funding level.

Partnerships for Teacher Preparation.—The President has committed $10 million in fiscal year 2000 to create a new and vibrant American Indian Corps of Teachers (AICT). This Corps, aimed at producing 1,000 new teachers for schools serving American Indian students, would provide $5 million for fellowships to college students majoring in education programs and $5 million for professional development programs in Indian Country to support current teachers. We believe that the Tribal Colleges and Universities are the ideal catalysts for this initiative and request the addition of report language specifying this as a Tribal College program. We urge Congress to support this important proposal, by providing report language and the full amount requested in the President's fiscal year 2000 budget.

Greater Support of Title IX of Improving America's Schools Act.—This title supports adult education programs for American Indians that are offered by state and local education agencies, and by Indian tribes, institutions, and agencies. Unfortunately, the section has not been funded since fiscal year 1995. As mentioned earlier, the Tribal Colleges provide adult education classes to their communities. Yet the Tribal College Act does not include funding for remediation and adult basic education, as it only supports those students enrolled in postsecondary programs. But before many can even begin the course work needed to learn a productive skill, they first must earn a GED or in some cases, learn to read. According to a 1995 survey conducted by the Carnegie Foundation for the Advancement of Teaching, 20 percent of the students questioned had completed a Tribal College GED program before beginning formal classes at the Tribal College. At some schools, the percentage is even higher. For example, Lac Courte Oreilles Ojibwa Community College in Wisconsin reports that nearly one-third of its students had earned a GED through its tutoring and testing center. Clearly, the need for basic educational programs is tremendous, and Tribal Colleges need funding to support these crucial activities. The President's budget does not include funding for this Title, but the Tribal Colleges need a minimum of $5 million to provide limited support for the ever increasing demand of basic adult education services. Without this minimum commitment, how can we even begin to sustain and build upon the vitally needed services for our adult student populations? We hope that Congress addresses this serious oversight on the part of the Administration.

Tribal College Early Childhood Initiative.—This initiative is currently funded at $700,000 for fiscal year 1999 through Head Start discretionary funds. The program

is under the jurisdiction of the Administration on Children, Youth and Families (ACYF) and the Administration on Children and Families (ACF) of the Department of Health and Human Services. The Head Start Act requires a minimum of 50 percent of the teachers in Head Start agencies nationwide obtain not less than an associate degree in early childhood education of a field related to early childhood education by 2003. Currently, 76 percent of Indian Head Start agencies are staffed by individuals who have earned a child development associate certificate; and fewer than one-quarter of American Indian Head Start agency personnel have earned an associate of baccalaureate degree. By developing partnerships between the early childhood education programs at Tribal Colleges and Head Start programs within Indian Country, American Indian Head Start agency personnel can gain greater access to accredited college programs in their career field. The increase in staff knowledge, skills and aptitude will result in a positive effect on the health, early childhood development and school readiness of the American Indian children served by this vital program. The Tribal Colleges request the Subcommittee to encourage this partnership by inserting report language recommending funding of $3 million in fiscal year 2000 for the continuation of this important program.

CONCLUSION

In light of the justifications presented in this statement and the expected enrollment increases at Tribal Colleges, we urge the Subcommittee to increase funding for the specific Tribal College programs mentioned here. Fulfillment of AIHEC's fiscal year 2000 request will strengthen the mission of these colleges and the enormous, positive impact they have on their respective communities and will help ensure that they are able to properly educate and prepare thousands of American Indians for the workforce of the 21st century. As the latest Carnegie Report on Tribal Colleges stated, "Now, as strongly as ever, we repeat our conviction that Tribal Colleges deserve continued support. Their value has been proven, but their vision is not yet fulfilled" (Native American Colleges: Progress and Prospects, Carnegie Foundation for the Advancement of Teaching, 1997). Tribal Colleges have been extremely responsible with the Federal support they have received in the last 18 years, and have proven themselves as a sound Federal investment. Therefore, we ask for your continued support.

Thank you again for this opportunity to present our funding requests before this Subcommittee. We respectfully ask the Members of this Subcommittee for their continued support and full consideration of our fiscal year 2000 appropriations request.

Prepared Statement of Dr. Sherry R. Allison on Behalf of the National Indian Education Association

The National Indian Education Association (NIEA), the oldest national non-profit organization representing the education concerns of over 3,000 American Indian and Alaska Native educators, school administrators, teachers, parents, and students, is pleased to submit this statement on the President's fiscal year 2000 budget as it affects Indian education. NIEA has an elected board of 12 members who represent various Indian education programs and tribal constituencies from throughout the nation. The following are NIEA 19s funding recommendations for programs authorized under Labor, Health and Human Services and Education appropriations.

DEPARTMENT OF EDUCATION

President Clinton has proposed several new programs for fiscal year 2000 in his 21st Century Schools initiative which focuses almost entirely on improving the human and physical infrastructure needs of public schools. The Administration's fiscal year 2000 proposals include: the second year of funding for Class Size Reduction which plans to add 100,000 new teachers; a new School Construction and Modernization effort; accountability measures for ending social promotion; expanding after-school activities and an American Indian Teacher Corps program which proposes to increase the number of American Ind ians entering the teaching profession by 1,000. Most of these, if funded, would mean additional education resources for Indian students attending public and Bureau of Indian Affairs (BIA) schools and those Indians entering postsecondary education. The last few appropriation cycles have shown several school construction/bonding proposals which have failed to be funded for various reasons.

Office of Indian Education (OIE)

For fiscal year 2000, the Department of Education has requested $77 million to fund Office of Indian Education's formula grants to Local Education Agencies

(LEAs), partially restore discretionary funding for OIE and fund certain National Center for Education Statistics (NCES) surveys. This amount, in addition to LEA grants, would include a partial reinstatement of discretionary grant programs, minimal funding for the National Advisory Council on Indian Education (NACIE) and funding to carry out objectives of the Executive Order on American Indian and Alaska Native Education signed by President Clinton on August 6, 1999. In 1997, budget authority for OIE transferred from Interior to Labor, Health and Human Services, and Education Appropriations.

Partial funding has been restored for OIE's discretionary program called Special Programs for Indian Children. NIEA requests the Committee's support for full reinstatement for other discretionary programs in adult education, adult literacy and Indian fellowships. The Administration's support for Indian students throughout its other programs is well established and funding is desperately needed by the Indian community, however, few Departmental initiatives are available for Indians attending postsecondary institutions or needing adult education services. This educational gap prevents full educational access generally assured other students. NIEA's fiscal year 2000 request proposes to fill this educational inequity.

The following are NIEA's recommendations regarding OIE funding by category:

Formula Grants to LEAs.—For fiscal year 2000, the Administration has requested $62 million for OIE's formula grant program to public schools which is level funded with fiscal year 1999. Formula grants are authorized under Title IX, Subpart 1 of the Improving America's Schools Act of 1994. The Department estimates that this funding assists 461,000 Indian students attending public and Bureau of Indian Affairs schools. In fiscal year 1999 there were 415,297 public school Indian students and 45,485 BIA Indian students receiving services through this program. The number of grants awarded in 1999 included: 1,120 public schools; 84 BIA-grant/contract schools; and 70 BIA-operated schools for a total of 1,274 grantees.

Special Programs for Indian Children.—The fiscal year 2000 request is $13.3 million and is $10 million over fiscal year 1999. NIEA fully supports the initiatives being supported by this funding. The Administration proposes to fund a new initiative called the American Indian Teacher Corp that would be funded at $10 million. All Subpart 2 programs are authorized by Title IX of the Improving America's Schools Act. The two currently active and proposed authorizations under Subpart 2 include:

—*Improvement of Educational Opportunities for Indian Children (Section 9121)*.—Under this authority, discretionary grants are awarded to State Education Agencies (SEAs), local educational agencies, Indian tribes and organizations, and institutions of higher education to improve Indian student achievement through such programs as early childhood education, drop-out prevention, and school-to-work and secondary school higher education transition programs. In fiscal year 1999, $1.4 million is available to award seven grants averaging $200,000. The Administration requests level funding for fiscal year 2000. NIEA fully supports this initiative.

—*Professional Development (Section 9122)*.—Under this authority, discretionary grants are awarded to institutions of higher education, SEAs, LEAs, Indian Tribes and organizations, and BIA-funded schools in consortium with institutions of higher education. The programs goal is to increase the number qualified Indian individuals in professions serving Indian people. Individuals receiving funding under this program are required to secure employment in a field that benefits Indians. In fiscal year 1999 the department will fund approximately eight 3-year grants serving 270 students with $1.8 million available for this program. The Administration requests level funding for fiscal year 2000. NIEA requests funding this category to a level of $3 million.

—*American Indian Teacher Corp (Section 9122)*.—This new program would combine several program elements in a manner that effectively trains Indian students to work in schools with concentrations of Indian children and youth. Tribal colleges would assume a major role under this program as would postsecondary institutions that offer teacher training to develop and ensure that programs reflect the needs of Indian students. TCCCs would facilitate the recruitment effort working with paraprofessionals already in the field in Indian communities. The $10 million request would provide training for an initial cohort of 500 prospective teachers. NIEA fully supports this initiative.

Special Programs for Indian Adults (Section 9131).—No funds are requested for this program in the fiscal year 2000 budget. This program was last funded in 1995 when it received $5.4 million for 30 projects to carry out educational programs specifically for Indian adults. NIEA has identified adult education for American Indians and Alaska Natives as one of the four priorities urgently needed by Indian Country.

NIEA strongly recommends $5 million for reinstatement of the Special Programs for Indian Adults.

National Activities.—The Administration requests $1.7 million in fiscal year 2000 to augment the Year 2000 National Center for Education Statistics (NCES) Schools and Staffing Survey (SASS) and other proposed research initiatives. The fiscal year 2000 request is $1 million over fiscal year 1999. The data collection effort would ensure that American Indian students are included in upcoming NCES surveys that will yield additional information on American Indian learners.

NIEA appreciates the targeted increases for Indian education, but continues to be concerned that studies on American Indian and Alaska Native students are not already a part of the Department's data gathering effort. All other ethnic populations receive considerable research results without having their respective program budgets cover the cost. A 1996 report by the United States Commission on Civil Rights titled the "Equal Educational Opportunity Project Series, Vol. 1" found that Department of Education data on student characteristics was lacking among students from American Indian, Asian and other national backgrounds. The report stated that "accurate, reliable and complete data on these ethnic groups are vital for the efforts of the education community to assess the needs of all student sub-populations." The report recommended that documents from the Department of Education's Office of Educational Research and Improvement (OERI), and other federal agencies that contain data utilized by policy and decision makers, should include information on these populations. NIEA echoes this position and recommends that the Department of Education make a concerted effort to provide research data for all ethnic categories when conducting studies and that they do so with funds requested through their own research department.

Tribal College Executive Order.—At the release of the Department's budget, no numbers were available for funding recommendations for the Tribal Colleges Executive Order which was funded in fiscal year 1999 at $200,000. NIEA has been informed by the Department that other agencies will have their resources combined for the Order's implementation. We are not sure which agencies will be asked to contribute.

The National Advisory Council on Indian Education (NACIE).—For the past four appropriation cycles, NACIE has been funded at $50,000. NIEA recommends funding for NACIE in the amount of $500,000 in order for it to re-establish an office within the Department of Education and hire full-time staff. NIEA is aware that appropriation language in the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee Report from September, 1998 (S.R. 105–300) recommends funding NACIE at $200,000. NIEA supports this recommendation and encourages the Department to support our higher recommendation. We are concerned that the Administration's request would neglect the inclusion of one of its own commissions, particularly in its obvious concern for Indian education.

NIEA requests that funding be made available for NACIE in light of its advisory role called for in the implementation of the Indian Education Executive Order signed by President Clinton in August, 1998. Since several requirements are to be completed during the first year, it is critical that NACIE re-establish an office to facilitate its executive order mission. NACIE currently has no permanent office and must rely on OIE staff to carry out minimal functions. Discussions with the NACIE Chair indicate that communications between NACIE and OIE staff have been minimal. NIEA has made every effort to involve NACIE in several Indian education initiatives including keeping the council updated on Executive Order functions.

OIE Fellowship Program.—This program is not recommended for funding in the fiscal year 2000 request. In lieu of funding this program, NIEA recommends increasing the amount of funding available under OIE's Professional Development to $3 million in fiscal year 2000 and $4 million in fiscal year 2001.

OIE Administration.—Since fiscal year 1997 funding for OIE administration has been covered under the overall Department of Education's General Administration account. A budget footnote in the Education Department's 2000 budget request indicates that $2.8 million will be available for OIE administration. NIEA encourages the Administration and the Department of Education to use a portion of these funds for the reinstatement of the NACIE office.

OTHER DOED INDIAN EDUCATION-RELATED PROGRAMS

NIEA fully supports the Indian set-asides for the following Department of Education programs.

Class Size Reduction Initiative.—The fiscal year 2000 request is $1.4 billion to support an estimated 38,000 teachers in early grades under the second year of the Administration's class size reduction plan. In fiscal year 1999, $1.2 billion was ap-

propriated toward the seven-year plan in which 30,000 teachers are expected to be hired in the first year. The initiative's goal is to hire 100,000 new teachers over seven years. The Administration proposes to spend $7.3 billion over seven years to reduce class sizes particularly in urban areas. The Department estimates that approximately $3.5 million would be available in fiscal year 1999 and $4 million in fiscal year 2000 for American Indians and Alaska Natives. NIEA supports this initiative.

Reading and Literacy Grants.—The fiscal year 2000 request is $86 million and is $26 million over the fiscal year 1999 funded amount. NIEA fully supports the funding request for this program. NIEA is concerned, however, that there is no set-aside for BIA funded schools in the Reading Excellence Act. This 1.5 percent set-aside was included in the original America Reads program, but not in this Act. NIEA strongly encourages the committee to support a technical amendment that would include Indian tribes and BIA schools as eligible for a tribal set-aside of 1.5 percent.

Goals 2000.—The fiscal year 2000 request is $491 million and is level funded with fiscal year 1999. NIEA supports the President's request for Goals 2000. One percent of Title III funds for Territories and BIA-funded schools are used to support comprehensive, systemic education reforms to improve teaching and learning. NIEA requests at least $3.2 million for BIA-funded schools in fiscal year 2000. Approximately 43,000 Indian students are to be served.

Safe and Drug-Free Schools.—The fiscal year 2000 request is $591 million and is $25 million over fiscal year 1999. NIEA supports the fiscal year 2000 request for Safe and Drug-Free Schools. State grants under this program total $439 million. BIA schools receive a one percent set-aside, which in 1999 was $5.3 million. A similar amount for Indian schools is to be available in fiscal year 2000. The fiscal year 1999 request is expected to benefit approximately 40,000 Indian students. NIEA fully supports this initiative.

School-To-Work.—The fiscal year 2000 request is $55 million and continues the phase-out of the School-to-Work program in 2001 with States or other vocational education dollars continuing the program. NIEA supports the President's request for this program. The fiscal year 2000 request is $55 million with an equal request from the Department of Labor bringing the total program to $105 million. Fiscal year 1999 funding was $125 million each Department. Up to one percent of program funds are set-aside for programs to help Indian youth acquire the knowledge and skills they need to make a smooth transition from school to career-oriented work and further education and training. The amount going to Indian students in fiscal year 2000, based on prior year allocations, should be $1.2 million.

Title I, Grants to LEAs.—The fiscal year 2000 request is $6.6 billion and is $300 million over 1999. Title I, Education for the Disadvantaged, covers four programs: Title I basic grants; Title I concentration grants; Title I targeted grants; and capital expenses for private school children. The fiscal year 1999 request for Title I Basic Grants was $6.3 billion, an increase of $788,000 (less than 0.1 percent) over 1998. The BIA set-aside amount under the fiscal year 2000 appropriation would be $51 million and serve approximately 25,000 Indian students. NIEA supports the fiscal year 2000 funding recommendation.

Title I, Comprehensive School Reform.—The fiscal year 2000 request is $150 million and is $30 million over fiscal year 1999. This Title I initiative funds research based school-wide reform. Under this proposal, the BIA would share a 1 percent set-aside with U.S. Territories. The BIA portion would be approximately $1 million. NIEA supports this request.

Title I, Even Start.—The fiscal year 2000 request is $145 million and is $10 million over fiscal year 1999. The Even Start program supports local projects that blend early childhood education, parenting instruction, and adult education into a unified family literacy program. The fiscal year 2000 Indian set-aside amount is estimated at $2.2 million. NIEA fully supports this program.

Eisenhower Professional Development State Grants.—The fiscal year 2000 request is $335 million and is level funded with fiscal year 1998 and fiscal year 1999. NIEA supports this program. The Eisenhower Professional Development program emphasizes improvement of instruction in mathematics, science and other professional development areas. The fiscal year 2000 Indian set-aside amount under this program is $1.7 million, comparable with fiscal year 1999.

Impact Aid.—The fiscal year 2000 request is $724 million and is $100 million less than fiscal year 1999. The Administration's request would provide the following allocations: Basic—$640 million; Special Education—$40 million; Heavily Impacted Districts—$0; Facilities Maintenance—$5 million; Construction, $7 million; and Payments for Federal property—$0. NIEA supports the National Association of Federally Impacted Schools (NAFIS) request of $944 million which proposes the following allocations: Basic—$754 million; Heavily Impacted Districts—$77 million; Special

Education—$50 million; Payments for Federal property—$43 million; Construction—$14 million; and Facilities Maintenance—$6 million.

Impact Aid compensates school districts in areas where large numbers of children live on, or are associated with, Federal property such as Indian reservations or military bases. In 1999 the Department estimated that over 124,000 Indian children living on Indian lands would generate approximately $300 million, well over the fiscal year 1998 amount of $214.5 million for local school districts. In fiscal year 2000, the following estimates show how much support Indian students may rate by category for public schools: Basic—$296 million; Special Education—$20 million; and School Construction—$4 million. The total fiscal year 2000 amount Indian students may generate under the Administration's request is $320 million.

Education for Homeless Children and Youth.—The fiscal year 2000 request is $31.7 million and is $2.9 million over 1999. NIEA supports the fiscal year 2000 request. Under this program, the BIA receives a one percent set-aside for homeless students served by the BIA. This amount is $100,000.

Bilingual Education.—The fiscal year 2000 request is $415 million and is $35 million over 1999. NIEA supports the Administration's request for Bilingual Education. BIA schools are eligible to apply for Bilingual Education funding directly through the Department of Education. In fiscal year 1999 the amount of grants to BIA schools was $749,000. Funding is distributed through grants to school districts to address the severe academic problems of school children who are limited English proficient. The Department estimates that 182,000 American Indian students in BIA and public schools will receive bilingual education assistance in fiscal year 1999. Under previous allocations, the Bilingual education program has included comprehensive reform funding designed to retain native languages of Indian communities. NIEA strongly encourages continuance of this effort.

Special Education Grants to States.—The fiscal year 2000 request is $4.3 billion and is $4 million over 1999. The Individuals with Disabilities Education Act (IDEA) was reauthorized in 1997 as Public Law 105–17. BIA schools receive 1 percent for the education of children 5–21 years with disabilities who live on reservations. An additional .25 percent is allocated for distribution to tribes and tribal organizations to provide for the coordination of assistance and related services for children aged 3–5 with disabilities in reservation schools. The set-aside amount in the fiscal year 2000 budget request is $52.9 million and is $7 million over 1999. Approximately 7,000 Indian students with disabilities would be served with Special Education funding. NIEA still strongly supports a set-aside amount of 1.5 percent. NIEA supports the increased amount.

Special Education Grants for Infants and Families.—The fiscal year 2000 request is $390 million and is $20 million over fiscal year 1999. The Indian set-aside under the request is $4.8 million and is $300,000 over 1999. NIEA supports the $4.8 million request for Grants for Infants and Families program. BIA schools receive 1.25 percent for distribution to tribes and tribal organizations for the coordination of assistance in the provision of early intervention services to children aged birth to 2 years.

Vocational Rehabilitation State Grants.—The fiscal year 2000 request is $2.3 billion and is $35 million over fiscal year 1999. NIEA supports the Presidents fiscal year 2000 request. Within the Vocational Rehabilitation State Grants program is the Grants to Indians section that is recommended for funding in the fiscal year 2000 request at $23.4 million. NIEA fully supports the Grants to Indian program. Funds for this program are based on a .5 percent set-aside. These critical dollars provide vocational rehabilitation services to 7,000 American Indians with disabilities living on reservations.

Education Technology.—The fiscal year 2000 request is $570 million and is $20 million less than 1999. The program includes a Technology Literacy Challenge fund, Technology Innovation Challenge Grants, and Regional Technology in Education Consortia. American Indians are estimated to benefit with approximately $2.3 million in Technology Literacy Challenge funds in fiscal year 1999. NIEA supports the higher fiscal year 1999 funding level for this program.

Protection and Advocacy of Individual Rights.—The fiscal year 2000 request is $10.9 million and is level with fiscal year 1999. The request would support systems in each state to protect and advocate for the legal and human rights of individuals with disabilities. These systems pursue legal and administrative remedies to ensure the protection of the rights of individuals with disabilities under federal law. NIEA supports the Indian set-aside in fiscal year 2000 is estimated at $75,000 and is level with fiscal year 1999.

Fund for the Improvement of Education (FIE).—The fiscal year 2000 request is $139.5 million and is $7.5 million less than fiscal year 1999. This program supports a variety of activities aimed at stimulating reform and improving teaching and

learning. FIE also funds through the States a portion of the Title I Demonstrations of Comprehensive School Reform which provides resources and incentives to apply research findings and strategies to help turn around failing schools. NIEA requests the fiscal year 2000 Indian set-aside amount of $81,000 and is level with fiscal year 1998 and fiscal year 1999.

Alaska Native Education Equity.—The fiscal year 2000 request is $10 million and is level with fiscal year 1999. NIEA fully supports the fiscal year 2000 request. The fiscal year 2000 proposal will fund an Educational Planning, Curriculum Development, Teacher Training, and Recruitment program at $5.1 million; a Home-based Education for Pre-School Children program at $3.8 million; and a School Enrichment program at $1.1 million. The Alaska Native Education Equity program funding request provides funding for continuation of projects that address the barriers preventing Alaska Native students from achieving to higher academic standards.

Vocational and Adult Education.—The fiscal year 2000 request is $1.1 billion and is recommended at $9 million over 1999. Under the Basic Grants program there is an Indian and Hawaiian Natives set-aside in the amount of $15.4 million that is recommended at level funded with fiscal year 1999. Additionally, there is a Tribally Controlled Postsecondary Vocational and Technical Institutions program recommended at $4.1 million, level with fiscal year 1999. NIEA fully supports funding for these programs as requested by the American Indian Higher Education Consortium (AIHEC).

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration for Children and Families

Head Start.—The fiscal year 2000 request is $5.3 billion and is $607 million over 1999. NIEA supports the fiscal year 2000 budget request. The Indian Head Start program under the fiscal year 2000 budget would receive $146.6 million which is $25.3 million over 1999. In 1998, over 21,600 American Indian and Alaska Native children attending Head Start If the budget request is approved, Indian communities should see an increase in Indian Head Start programs and enrollment. Currently there are 150 Indian Head Start programs serving Indian communities.

If enacted, this increase would be the largest in history, and would enable Head Start to serve an additional 42,000 children and bring the total national enrollment to 877,000 children. Under the Clinton administration, funding for Head Start has already increased by 68 percent, and enrollment has increased by over 200,000 children, reaching 835,000 children in fiscal year 1999. The fiscal year 2000 budget request would increase funding to nearly double the level when the President took office, keeping continues the Administration's commitment to expanding the Early Head Start (EHS) program that serves low-income families with children under three years old. The fiscal year 2000 budget request would serve 7,000 more EHS children, well on the way to the goal of doubling the program by 2002. The increase also includes approximately $250 million in new funds to continue to improve program quality.

PREPARED STATEMENT OF HON. SHARPE JAMES, MAYOR, NEWARK, NEW JERSEY

Mr. Chairman and Members of the Subcommittee: Thank you for giving me the opportunity to submit testimony about an innovative science education project being undertaken by the Newark Museum that is critical to the people of Newark, New Jersey. Newark is truly at a crossroads—we are a City with all of the problems of many major urban centers, but we are also a City with vast potential. We have begun to turn the corner—there is a renewed vitality and sense of optimism in Newark.

The Newark Museum seeks $2.0 million to support the Science Initiative. The City of Newark has committed $1.7 million dollars to date toward the preparatory collections care necessary to make this initiative possible. Additionally, The Museum plans a $5 million dollar operating endowment fund based upon a public/private partnership to assure adequate on-going support, of which $1.2 million has been raised to date. Research has shown that the ongoing maintenance cost of science galleries is several multiples of that of art galleries.

The Newark Museum is recognized as one of the nation's leading cultural institutions. It is located in Newark, New Jersey's largest city, and within Essex County, the State's most densely populated. The Museum's constituency is economically and ethnically diverse, reflecting the distinctive character of the city, northern New Jersey and the metropolitan region. In 1998, The Newark Museum served an audience of 462,000 children and adults.

Science has been a part of The Newark Museum since the donation in 1912 of local physician Dr. William Disbrow's collection of natural science specimens. Subsequently, the Mini Zoo was added as part of the Junior Museum's Nature Corner in 1926, and the Dreyfuss Planetarium in 1953, to expand the visitor's learning experiences and appreciation for the sciences. The Newark Museum's natural science collections of 74,000 specimens in the areas of geology, botany and biology are being utilized today in programs that allow for participatory and inquiry-driven experiences, to engage visitors in meaningful science learning. Science-related programs draw more visitors to The Newark Museum than any other offering, despite the fact that the science galleries have been closed for more than a decade. Realizing the opportunity to attract larger audiences and better serve Newark and New Jersey residents, the Museum has embarked on a new science initiative. It will enable the Museum to reopen the science galleries and builds upon the Museum's proven track record of excellence in interdisciplinary arts and humanities programs.

THE NEWARK MUSEUM NEW SCIENCE EDUCATION INITIATIVE: RESHAPING SCIENCE EDUCATION

The Newark Museum's New Science Education Initiative was conceptualized and is being executed by a dedicated team of community-based educators, scientists and business people working alongside Museum trustees and staff. Members of the Science Team bring nationally recognized expertise with an understanding of the particular needs of communities in Newark and throughout New Jersey.

The plan calls for the creation of a major permanent exhibition based upon its natural science collection. The exhibition, called Making Sense of the Natural World, will explore scientific phenomena through natural history specimens and live animals. Museum audiences will participate in mindful science learning through stimulating and engaging experiences that integrate the collections, Dreyfuss Planetarium and Mini Zoo. This gallery, along with the Museum's plan to institutionalize cohesive science education programs parallel to its distinguished art and culture programs, is the core of The Newark Museum Science Education Initiative.

The cohesive science education at The Newark Museum will entail greater use and dissemination of our science gallery, planetarium and live animal resources, thus providing new learning opportunities for individuals, families, schools, and community organizations. This initiative also allows us to safeguard the thousands of scientific specimens, so critical to its success, in proper housing both in the exhibition and in technologically advanced, environmentally appropriate behind-the-scenes storage

In planning the new Science Initiative, Museum staff and Trustees have been guided by the principles contained in Goals 2000 and by New Jersey's recently adopted Core Curriculum Content Standards for K–12 education. Critical thinking, mathematical, and scientific understanding will be fostered as visitors question, experiment, compare, and analyze real specimens from the Museums science collections, and participate in planetarium and Mini Zoo programs designed to effectively communicate complicated and abstract science concepts.

The science plan will also include a Science Resource Laboratory for teachers, which will provide them with a space to research and test curriculum ideas for hands-on activities in the natural and planetary sciences. Based on the results of research conducted with Newark educators, these monthly multi-session and one-time in-service teacher professional development workshops will provide teachers opportunities to become more comfortable teaching science and meet the state-mandated re-certification requirements. The same Science Labs will be used by school classes and in after school and weekend programs to reinforce science concepts that are introduced in Making Sense of the Natural World, the projected new exhibition.

For high school students from Newark and other state urban districts, the Science Initiative calls for a Science Career Ladder. These innovative programs are designed to provide "at-risk" teens with critical exposure to careers in science and to teach workplace ethics and behavior. This builds upon an already successful YouthAlive program at the Museum. In addition, the plan will provide a Science Internship Program, which will offer students a year-long experience in scientific research, collections management, and the planetary sciences at The Newark Museum.

A major focus of the plan is The Newark Museum Dreyfuss Planetarium, the first in New Jersey. This summer, the Planetarium will receive a new star projector, a Zeiss ZKP3 funded by the City of Newark in recognition of the major contribution that Planetarium programs have made to the education of the city's youth. The ZKP3 is the ultimate machine to teach and demonstrate any curriculum related to astronomy and space travel. Planetariums, better than any other facility, are unsurpassed at simulating the night sky and the universe. The visitor is immersed in an

environment which saturates the senses. The planetarium staff is investigating new ways in which a traditional planetarium can evolve to be a model to effectively serve Newark and New Jersey teachers and students, including the possibilities of distance learning and other innovative electronic methods of extending its reach beyond the domed theater. Recent collaborations with physicists at Rutgers University and New Jersey Institute of Technology have convinced us that the Planetarium can actively participate in a range of high technology activities, including serving as a public dissemination point for the extraordinary images of the Earth that NASA has collected.

The Museum is also formulating new approaches and designs for updated animal habitats in the Mini Zoo. The majority of these dwellings are in excess of ten years old, and may not use animals as effectively as possible in telling an ecologically-oriented story. The Mini Zoo will be upgrading its enclosures, which will likely offer mixed-species exhibits. This will allow for a more comprehensive examination of climate areas like deserts and rain forests and encourage displays on such topics as family style, camouflage, and biodiversity. New animals will be acquired that illustrate these themes most effectively. The Mini Zoo provides critical training for college students in captive wildlife management and science education. It offers programs in humane treatment of animals, called Don't Get that Exotic Pet Yet. These include such topics as why these kinds of animals do not make good household pets, care and maintenance of exotic pets, selecting a veterinarian, what to look for in a pet shop, and the illegal pet trade. Mini Zoo school programs, like all science programs, are designed to address Core Curriculum Content Standards, and address such issues as adaptation, ecosystems and taxonomy.

THE NEW NATURAL SCIENCE EXHIBITION, MAKING SENSE OF THE NATURAL WORLD

This gallery, intended primarily for a family and elementary school audience, will be one of the few in the country to combine the best of natural history museums and science centers by marrying actual biological, geological and botanical specimens with hands-on, inquiry-driven activities.

In this exhibit, visitors will experience the wonder of nature's diversity and then look at collections the way scientists look at them. They will begin to learn that natural history specimens individually and collectively provide volumes of information about science. They will understand how ordering the natural world led to the realization that the Earth is constantly changing and that life adapts to those changes. Moreover, they will appreciate that evidence of those changes is as close as their own backyard.

Recurring throughout the exhibit will be the concepts of bio-complexities and dynamic geological forces as fundamentals of the natural world. The museum's striking collections will be the vehicle for explaining—making sense of—these concepts as they relate to living and non-living systems, globally and locally.

The exhibition will be divided into five sections. The first is an Introductory Gallery, called the Diversity Arc, in which visitors will realize that by uncovering relationships within groups of specimens, scientists have been able to order and make sense of the diversity around them. Visitors will meet their video host at the first of several stations that are located throughout the exhibit. The host is a museum scientist who will guide visitors' observations and enhance their understanding of the exhibit's concepts. The host is one of the ways the exhibit will depict people as part of nature and interpreters of it. It will serve to put the exhibit components into context for the visitor.

In the second gallery, The Dynamic Earth: Forces of Change, sound and light will give visitors the feeling of being present at the beginning of the Earth. A short video will elaborate on the formation of the planet, plate tectonics and climate. Video animation will be used to communicate abstract geological concepts. Specimens will be displayed that illustrate the products of geological activity, climate change and glacial activity. Mineral and rock specimens will be chosen for the stories they can tell. Fossils, such as Glossopteris, found on today's widely separated continents, will show how tectonic forces split the continent on which the fern once grew.

Next, the visitor will encounter Life Adapts to Change, which will show the tremendous variety of environments on the Earth—the consequences of where continents and oceans are located today, and climate. Specimens from the African Savannah will show how different species have adapted to a unique biome, the grassland, through color, behavior and structure. The exhibit also contains an interactive natural selection component explaining the process. The remainder of the exhibit will illustrate two different kinds of adaptations to the environment: structural and behavioral. For example, grazing animals, such as deer and bison, have evolved teeth and jaws that can chew tough grasses. Sea otters have evolved tool-using

skills to open clams by striking them on rocks. Concepts that intersect with the Museum's Mini Zoo will be presented and the connections made.

At this junction, visitors will have the choice of either continuing to Collections: Tools of Knowledge or Diversity in Your Backyard: New Jersey Highlands. In Collections: Tools of Knowledge, visitors will discover that science is a dynamic, ongoing activity that uses specimens and collections as tools to make sense of the natural world. In this section, visitors explore how science is actually conducted. Scientists will tell their own story of how they collect data and analyze it, and there will be equipment which visitors can manipulate in activities designed to mimic the work the scientists perform. For most of the population, science is an abstract art, almost like magic. This area of the exhibit will assign the tasks of the scientist to the visitor, making the process of science much more concrete.

The final, and largest, section is called Diversity in Your Backyard: New Jersey Highlands, which will feature a re-creation, in the form of a walk-in diorama, of an oak-hickory forest biome of the New Jersey Highlands. It is a demonstration of how and why the interdynamics of geology and biology creates an ecosystem. Using New Jersey as a backdrop, this gallery will provide specific examples of Dynamic Earth and Adapting to Change in a recreated environment of the New Jersey Highlands. This will allow visitors to apply the complex ideas introduced earlier to examples familiar to them and to make sense themselves of the natural world. A tented "field station" will offer opportunities for hands-on activities. The story has several chapters: a Lake Story; Local Adaptation Stories; Microworld of the Pond Story; Greenhouse story; Geologic Processes in New Jersey story, which includes geologic processes as seen in the rock formations of the simulated cave; the Watershed Story; and the History Story, which will show how this area changed over the past 20,000 years.

We hope that you will give every consideration to funding this project.

PREPARED STATEMENT OF TOM MEIER, PRESIDENT, ELMIRA COLLEGE, ELMIRA, NY

Mr. Chairman, thank you for this opportunity to submit testimony for the record regarding Elmira College's proposed Technology Enhancement Initiative.

Today, unlike any other time in history, we have a substantial opportunity to apply the information age technologies to schools that are so effective outside the classroom for educational purposes. For schools to make the most of this opportunity, they must rethink education from the ground up.

The power of information technologies to reshape education is already becoming unmistakable. In scattered locations around the country, schools are using state-of-the-art technologies and interactive multi-media to engage students more actively in learning and to teach them skills they will need to thrive in an information based workplace and world. This is particularly true with non-traditional students who have little if any access to traditional classrooms and educational services.

As information age infrastructure is developed, more and more students and teachers will gain access to a global web of information and exchange ideas, services and education globally.

The Internet and other information technologies are bringing interactive instruction to schools in our cities and suburbs. Importantly, the past several years have witnessed a stronger focus on providing those information technologies in rural areas of the country. These technologies are allowing students to build "communities" with their counterparts around the world and create lifelong beneficial links between schools and the communities around them.

Taking advantage of this new capability will require profound changes in the roles of teachers, students and schools. Instead of being the repository of knowledge, teachers will be guides who will help students navigate through electronically accessible information. They will use the new technologies to build networks with each other, with parents and students, with academic and industrial experts and with other professionals.

In order to ensure that students (K–12, undergraduate, graduate, continuing education or professional development students, students in rural areas) receive the full potential of the technology age, the technological access must exist in flexible locations and provide continuous access to their extended communities. Equally as important, teachers must receive extensive training in how to use existing and emerging information technologies and how to design and implement appropriate curricula for a state-of-the-art 21st Century classroom.

To make technology a viable instructional and professional development tool requires schools to have enough computers to provide full easy access for all students including students with disabilities.

Institutions of higher education are central to the national effort to ensure that all students and teachers are equipped to take full advantage of the technology era. By providing education, training, and technical assistance these institutions can work in partnership with local school districts, human service agents and professionals to address problems associated with the rapid onset of the information age, including: educational, economic and social infrastructure of their surrounding communities.

Elmira College is an institution of higher education that accepts that responsibility willingly, recognizing the benefit to its students, students in surrounding school systems and community colleges, and individuals in nearby communities in need of continuing education or professional development. As such, it is implementing its "Technology Enhancement Initiative" to address its own and regional educational and technology training needs.

THE "TECHNOLOGY ENHANCEMENT INITIATIVE" AT ELMIRA COLLEGE

As it approaches the 21st Century, Elmira College, in Elmira New York, stands at an important crossroads in the development and expansion of its educational resources. To ensure its continued strength as a four-year institution of higher education the College is proposing the implementation of its "Technology Enhancement Initiative" to relocate and improve its technology infrastructure.

This initiative will address the ever-growing need in the southern tier of New York and northern tier of Pennsylvania for access to higher education, teacher technology education and training and professional development services. It will provide the College the opportunity to expand its technology resources and to meet its own and regional technological and services demands.

Elmira College proposes to establish a partnership with the federal government that will:

—Relocate, consolidate and improve all student and administrative computing services from McGraw Hall, which is handicapped inaccessible, to the Gannett-Tripp Library which is handicapped accessible;

—Upgrade existing "hub" hardware to state-of-the-art technology which will be able to meet and manage the demands of the upgraded system; and,

—Wire every dormitory, classroom and administrative meeting room as well as every faculty, academic, and administrative office building for direct access to the Gannett-Tripp Library, the Steele Memorial Public Library and an interface with the local public library system and with the Internet.

As a result of the improvement to its technological infrastructure, Elmira College will have the opportunity to expand existing and implement several new educational and training programs in partnership with local school systems and human service agencies. Specifically, the initiative will enable the College to:

—Offer access to higher education courses in 12 rural and underserved counties and 21 K–12 school districts (58,308 students), 8 community colleges and a variety of community sites via distance learning;

—Offer access to Elmira College library resources, including the federal depository at the College, at a variety of community sites via distance learning to underserved counties;

—Provide teacher technology education and training both on and off campus;

—Provide expanded professional development and technology education and training services;

—Provide leadership and technical assistance to local K—12 systems in the development of state-of-the-art technologically advanced classrooms and prepare its Education students (future teachers) and regional teachers to teach effectively in this technologically advanced era.

In addition to the obvious educational benefits that the Elmira College "Technology Enhancement Initiative" will have for the College and its students, there are several significant benefits for teachers in the regional community.

As a result of the Technology Enhancement Initiative, Elmira College will have the opportunity to work in partnership with regional school systems to address the education and training needs of their teachers and staff.

Elmira College will work to identify technology education and training expertise in the region and the nation and work with local school districts to develop critical professional linkages needed for the local school system to take full advantage of that expertise for their students.

In addition, as part of its own curricula, Elmira will provide expanded in-depth technology education and training for students in its Masters of Education programs.

The Technology Enhancement Initiative will provide Elmira College the ability to offer these teacher education and training courses through any of its distance learning capabilities to teachers in the classroom, on-site at their own schools, at local libraries, community colleges or even in the home. Graduate students at Elmira will continue their training within the local schools, but will have an increased ability to conduct classroom observations, information exchanges and training as a result of the Technology Enhancement Initiative.

To do so, the College will expand existing and implement new education, training and professional development programs, including courses such as Computers in Education, Interactive Media for Educators, The Internet for Educators, Video Production for Educators, and Microcomputer Applications for Educators. Finally, it will provide the College with the opportunity to play a leading role in improving the social and economic infrastructure of the region.

The Technology Enhancement Initiative will create an expanded opportunity for cooperation in the provision of higher education courses between Elmira College and local community colleges. It will help those institutions to provide timely and relevant programming at the same time it helps to prevent unnecessary duplication of academic programs and/or courses at Elmira or the community colleges.

As it is proposed, the relocation, expansion, and consolidation of all computing functions at Elmira College will provide three methods of distance learning in the future, including:

—Computer Based Research
—Internet Conferencing
—Compressed Video

Students and professionals in the field will have the ability to access education, training or professional development from home (if the connection exists) from libraries, other designated community sites or from any of the eight sites where Elmira currently provides minimal programming including:

—Bath
—Corning
—Ithica
—Owego
—Penn-Yan
—Watkins Glen
—Rome
—Syracuse (adult education)

Elmira College will have the ability to share faculty experiences across institutions and establish partnerships on select courses with regional community colleges, including general education courses, courses to support selected major requirements, and coursework providing a valuable supplement to existing offerings. Elmira College currently holds articulation agreements with three regional community colleges that will be expanded as a result of the Technology Enhancement Initiative. Those institutions include:

—Tompkins Cortland Community College
—Corning Community College
—Broome Community College

To enable the completion of this important initiative, Elmira College is seeking $4,399,000 million in federal support. To date, the College has invested $500,000 in campus infrastructure in preparation for the implementation of this initiative (these dollars are not counted as part of the official project cost, but are calculated into the College's contribution).

The College is firmly committed to the completion of the project and the implementation of these critical education and training programs. Therefore, the college plans to invest an additional $1.5 million in this project bringing its total investment to $2 million, or thirty-four percent of total project cost. Total project cost is $5,923,680 million.

Mr. Chairman, this initiative is critical to the long-term viability of Elmira College as well as the regional the K–12, undergraduate, graduate, continuing education and professional development systems in the southern tier of New York and the southern tier of Pennsylvania. We look forward to working with you in support of this initiative in fiscal year 2000.

Again, thank you for the opportunity to present this testimony for the record.

PREPARED STATEMENT OF JOHN KELLY, VICE PRESIDENT, RECORDING FOR THE BLIND AND DYSLEXIC

Mr. Chairman, Mr. Harkin, Members of the Subcommittee: I am John Kelly, Vice President of Recording for the Blind & Dyslexic (RFB&D), whose headquarters are located in Princeton, New Jersey, with thirty-three recording studios throughout the United States. It is on behalf of RFB&D that I submit this statement in support of our request for continued federal support of our mission as the nation's primary producer of recorded textbooks for people of all ages who cannot use standard print because of a visual, perceptual or physical disability. Additionally, it is to help provide them with the best education possible, in order to facilitate their entry into today's job market.

First, I want to thank the members of the subcommittee for the continuous support that you have given RFB&D since our first federal assistance, which began in 1975. This support, plus the support we receive through private philanthropy, allowed us this year to circulate more than 233,000 textbooks to approximately 55,000 borrowers. Increased federal support has been key to our ability to reach an increasing number of students, including an increasing number of severely dyslexic students.

RFB&D was founded in 1948 as a non-profit service for returning blind veterans of World War II—a G.I. Bill of Rights for blind veterans, as it were—and has grown into a national, private, volunteer-based organization serving as the national education library for people who cannot read standard print because of a disability. Although its headquarters are in Princeton, New Jersey, its volunteer readers are spread throughout the United States, as are its library users.

RFB&D distributes textbooks and other educational materials in accessible audio and digital sound and text formats. Our tape and digital library, with more than 77,000 titles, continues to grow, and is constantly updated to meet the needs of our student and professional users. Our books are provided free of charge to students of all ages, after a small registration fee, with students permitted to borrow as many texts as required for their course of study.

Our request to the subcommittee for fiscal year 2000 is for an appropriation of $7,000,000, an increase of $500,000 over the amount provided by the Congress last year. This amount is $1,000,000 more than requested in the president's budget. Federal grant support, which is approximately 25 percent of our total budget, will continue to be used for two significant initiatives.

1. Expanding the number of student borrowers through an aggressive outreach program: By the end of the year 2000, only 20 months from now, the number of borrowers dependent on us for their textbooks is expected to exceed 75,000 students. Since these students are entitled by both the Americans with Disabilities Act (ADA) and the Individuals with 1Disabilities Education Act (IDEA) to relevant educational materials, RFB&D believes that our federal appropriation represents an appropriate contribution towards this cost. Our 4800 highly trained readers are volunteers knowledgeable in the field in which they read; therefore, RFB&D is able to meet this need at a fraction of what it would cost government, whether local or federal, if it were required to produce these textbooks on their own.

2. Converting RFB&D's recording system from analog tape to digital format: RFB&D is well along in the multiyear project to convert its recording operations to the new digital technology. This change will have two principal advantages. First, it will allow visually impaired and dyslexic students to search and move around within a book in the same way that sighted students do. Second, it will permit books to be circulated on CD–ROM and electronically through the Internet. During 1999, RFB&D has begun the process of revamping its 33 recording studios.

RFB&D notes with pride that in making this request, we can report that the expanded service and private fundraising goals set in the financial management plan presented in January 1997 are being met. Between fiscal year 1996 and fiscal year 1998, the number of borrowers expanded by 40 percent and private cash contributions increased by 45 percent. This has only been possible through the untiring work and commitment of our volunteers, our career staff and this subommittee. We are pleased that we have been able to meet or exceed the performance standards which we set for ourselves in this plan.

Mr. Chairman, RFB&D and its student users are grateful for the support the subcommittee has provided in the past, and are hopeful that you will be able to approve our request of $7 million for fiscal year 2000. This level of support will assist RFB&D as it continues our joint efforts to serve the educational needs of disabled students throughout the United States.

RELATED AGENCIES

PREPARED STATEMENT OF THE NATIONAL MINORITY PUBLIC BROADCASTING CONSORTIA: NATIONAL ASIAN AMERICAN TELECOMMUNICATIONS ASSOCIATION; NATIONAL BLACK PROGRAMMING CONSORTIUM; LATINO PUBLIC BROADCASTING PROJECT; NATIVE AMERICAN PUBLIC TELECOMMUNICATIONS; AND PACIFIC ISLANDERS IN COMMUNICATIONS

The National Minority Public Broadcasting Consortia (Minority Consortia) submits this statement on the fiscal year 2002 appropriation for the Corporation for Public Broadcasting (CPB). Our primary missions are to bring a significant amount of programming from our communities into the mainstream of public broadcasting. In summary, our budget recommendations are that Congress:

—Support the Administration's request of $350 million for CPB for fiscal year 2002, a $10 million increase over fiscal year 2001.

—Recommend an increased allocation of CPB funds in fiscal years 2000, 2001, and 2002 for the National Minority Public Broadcasting Consortia to expand our programming capacity and to assist independent minority producers in converting to digital production.

The National Minority Public Broadcasting Consortia consists of the Asian American Telecommunications Association, the National Black Programming Consortium, Native American Public Telecommunications, Pacific Islanders in Communications and, currently, the Latino Public Broadcasting Project.

A federal appropriation of $350 million as requested by the Administration for CPB would be a reasonable, albeit modest, contribution toward our national treasure of public broadcasting. The debate of the past several years regarding public television and public radio has highlighted the great esteem in which it is held. We urge Congress to provide at least as much as has been requested by the Administration for CPB for fiscal year 2002.

Public broadcasting is particularly important for minority and ethnic communities. While there is a niche in the commercial broadcast and cable world for quality programming about our communities and our concerns, it is in the public broadcasting industry where minority communities and producers are more able to bring quality programming for national audiences. Additionally, public television is universally available, unlike costly cable channels. In 1994, CPB initiated research among Asian American and Native American communities which documented that respondents felt their communities were negatively stereotyped on commercial television that that public television had more realistic portrayals. (Reaching Common Ground: Public Broadcasting's Services to Minorities and Other Groups, July 1, 1994, pages 41–41 of the Appendix). This survey also revealed that both groups wanted increased visibility in public television and further recommended that there be expanded promotion of public broadcast programming utilizing Asian American and community groups and tribal organizations. Earlier CPB surveys of Latino and African American communities showed similar findings.

Increased Support for Multicultural Programming and the Minority Consortia.—Among the reasons why there should be increased funding for multicultural programming and for the work of the Minority Consortia are:

—CPB has received increased appropriations for the past two years and has the resources to increase its support for multicultural programming.

—It would be in keeping with the stated Congressional support for multicultural programming and for the role of the Minority Consortia in nurturing and producing this programming for public broadcast.

—The Minority Consortia organizations are in the best position to encourage and assist producers in our communities in the development of programming for public broadcast.

This is the Optimum Time to Fulfill CPB's Mission of Diversity.—The Congressional urging of CPB to increase its support for the Minority Consortia and for multicultural programming combined with two years of significant funding increases for CPB make this an ideal time for significant progress. It may be now or never.

We certainly appreciate the support the Minority Consortia has received from Congress and from this Subcommittee in particular. Since 1988, ten Congressional authorizing and appropriations reports have expressed support for the Minority Consortia and/or for increased multicultural programming on public television.[1]

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[1] House Report 100–825, report of the House Committee on Energy and Commerce on the Public Telecommunications Act of 1988; Senate Report 100–444, report of the Senate Commerce, Science and Transportation Committee, on the Public Telecommunications Act of 1988; House Report 102–363, report of the House Committee on Energy and Commerce on the Public Tele-

The Minority Consortia organizations, who receive jointly about $1.4 million in institutional support from CPB and who also administer the $3.2 million Multicultural Program Fund, have shared in past CPB budget reductions. Both our institutional support funds and the Multicultural Program Fund monies were reduced in fiscal years 1997and 1998 when CPB appropriations declined. Our fiscal year 1999 funding was the same as in the prior year. Our institutional support and the Multicultural Program Fund combined equal less than 2 percent of the CPB budget.

Now, however, we are entering a time period for which Congress has appropriated increased funding for CPB. The CPB fiscal year 2000 appropriation, which has not yet been distributed, is $300 million, a $50 million increase over fiscal year 1999. And the fiscal year 2001 appropriation is $340 million, an increase of $40 million over fiscal year 2000 and a $90 million increase over fiscal year 1999.

So already appropriated is a $50 million increase for fiscal year 2000 and an additional $40 million increase on top of that for fiscal year 2001. And what did Congress say about funding for the Minority Consortia for those two years? In the fiscal year 1998 House Appropriations Report (fiscal year 2000 CPB funding), Congress stated: "The Committee supports CPB's commitment to maximize resources with the goal of increasing multicultural programming for public television by formalizing partnerships among the Minority Consortia organizations, the CPB, the Public Broadcasting Systems, America's Public Television Stations, and individual television stations."

And in the fiscal year 1999 House Appropriations (fiscal year 2001 CPB funding) Congress stated: "The Committee recognizes the importance of developing multicultural programming through the National Minority Public Broadcasting Consortia."

The Minority Consortia has often noted in its Congressional testimony the changing demographics of our nation. It is common knowledge that we are rapidly becoming a more multicultural society, but political leverage is exceedingly slow to catch up with this reality. While collectively the communities we represent already comprise nearly 30 percent of the nation's population, that percentage is expected to be nearly 50 percent by the year 2050.

The testimony of CPB President Bob Coonrod before this Subcommittee on March 23, 1999 focused on the need to increase the diversity of public broadcasting offerings, including multicultural programming. We applaud CPB's public discussion of this need, and intend to work collaboratively with them and the entire public broadcasting community to help make this a reality. But in order to do this, the amount of funding allocated for the development of multicultural programming must substantially increase.

Digital Conversion Assistance.—Mr. Coonrod's March 23rd testimony also addressed the opportunities which digital technology will provide in the area of programming. It is both an opportunity and an expensive challenge. With stations able to broadcast on multiple channels, there will be a need for a tremendous amount of new, quality public broadcasting programming. There are costs involved in the conversion which go beyond the significant equipment and hardware needs of stations. It will also take additional money to produce programming for digital broadcast. All producers will face these new, higher costs. Film producers will need to use equipment that is high definition quality, and that is an expensive proportion. For producers will need to use 35 mm or super 16 film. Producers will need new, and expensive, field equipment and cameras in order to shoot in wide screen format. Most of the producers with whom we work do have not the finances for this new equipment. CPB is currently providing technical assistance and training to producers regarding digital conversion. However, independent and minority producers also need financial assistance in acquiring or accessing the means to produce programming for digital broadcast.

Work of the Minority Consortia.—The Minority Consortia organizations work both individually and collaboratively. In the past twenty years the Consortia organization

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communications Act of 1991; Senate Report 102–221, report of the Senate Commerce, Science and Transportation Committee report on the Public Telecommunications Act of 1991; House Report 102–708, report of the House Appropriations Committee on the fiscal year 1993 Labor, HHS, Education Appropriations Act (fiscal year 1995 CPB funding); House Report 103–156 report of the House Appropriations Committee on the fiscal year 1994 Labor, HHS, Education Appropriations Act (fiscal year 1996 CPB funding); House Report 103–553, report of the House Appropriations Committee on the fiscal year 1995 Labor, HHS, Education Appropriations Act (fiscal year 1997 CPB funding); House Report 104–659, report of the House Appropriations Committee on the fiscal year 1997 Labor, HHS, Education Appropriations Act (fiscal year 1999 CPB funding); House Report 105–205, report of the House Appropriations Committee on the fiscal year 1998 Labor, HHS, Education Appropriations Act (fiscal year 2000 CPB funding); and House Report 105–635, report of the House Appropriations Committee on the fiscal year 1999 Labor, HHS, Education Appropriations Act (fiscal year 2001 CPB funding).

have individually provided to public broadcasting's schedule hundreds of hours of programming addressing the cultural, social and economic issues of the country's racial and ethnic communities. Individually, each Consortia organization has been engaged in cultivating ongoing relationships with the independent producers community by providing technical assistance, program funding, programming support and distribution. We also provide numerous hours of programming to individual public television and radio stations.

On the collaborative front, the five organizations comprising the Minority Consortia are working to jointly write and publish a catalog, newspaper ads, Open Calls for Proposals, and a newsletter. Perhaps of most potential significance is our joint proposal of a five-part series of programs on race relations in America. We sent a solicitation for proposals to producers for this project in March. The series would consist of one program annually for five years, and would be undertaken with substantial input from CPB and PBS. We envision the project to be a mutli-layered presentation, i.e. utilizing enhanced broadcast applications such as extended interviews and data for Web-TV or Internet-linked use. The topic of this series is of national concern and we believe it is very important to explore why, for instance, in a period of unprecedented and sustained economic prosperity, that relations among the different races and cultures in our country are so troubled.

Currently the five consortia groups are in discussion with other public broadcast entities to pool and share resources to increase awareness of CPB's and Public Broadcasting diversity initiative. Some of these collaborations include centralizing program distribution with American Public Television (APT), creating minority outreach for stations with the Public Television Outreach Alliance (PTOA), and working with CPB to formulate a long range strategy for minority programming for public broadcasting.

The Minority Consortia organizations work collaboratively with a number of television stations, and hope to increase such working relationships.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we as minority communities in public broadcasting thank you for your long time support of our work on behalf of our communities.

PREPARED JOINT STATEMENT OF JANE WATKINS (ORLANDO, FL), PRESIDENT, NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS; DWIGHT RASMUSSEN (SALT LAKE CITY, UT), PRESIDENT, NATIONAL ASSOCIATION OF SENIOR COMPANION PROJECT DIRECTORS; AND NAN YORK (NEWPORT NEWS, VA), PRESIDENT, NATIONAL ASSOCIATION OF RETIRED AND SENIOR VOLUNTEER PROGRAM DIRECTORS

We are pleased to testify in support of fiscal year 2000 appropriations for the Foster Grandparent Program (FGP), Senior Companion Program (SCP), and Retired and Senior Volunteer Program (RSVP), known collectively as the National Senior Service Corps (NSSC) authorized by the Domestic Volunteer Service Act and administered by the Corporation for National and Community Service.

The National Directors Associations are membership-supported professional organizations whose rosters include the majority of more than 1,200 directors who administer NSSC programs across the nation, as well as local sponsoring agencies and others who value and support the work of NSSC programs.

While we the aggregate funding levels set forth in the President's fiscal year 2000 budget request for the Senior Corps proposes a modest increase in funding for the next fiscal year, we cannot fully support that request on several counts. First, the President's budget calls for significant increases in other programs of the Corporation for National Service, including AmeriCorps. As one of the three "streams of service" supported by CNS, we feel it imperative to at least secure parity in this year's annual appropriations process. In addition, given the continuing growth in need for senior volunteers and the fact that are programs are nowhere near the capacity of accommodating all of those who are qualified and wish to serve, we would be remiss were we not to advocate for program expansion during this time of robust performance in our economy.

Accordingly, we request that the Subcommittee on Labor, Health and Human Services, Education and Related Agencies appropriate a funding level sufficient to both sustain existing programming and promote expansion into unserved areas. Specifically, we request that the Subcommittee appropriate a funding level of $48.161 million for the Retired and Senior Volunteer Program (RSVP), $104.560 million for the Foster Grandparent Program, and $43.878 million for the Senior Companion Program.

These funding levels assume the following program components: .An increase in the volunteer stipend for Foster Grandparents and Senior Companions of $.05 per hour.

—An administrative cost increase of 3 percent in the Foster Grandparent and Senior Companion Programs and 8 percent in the Retired and Senior Volunteer Program.

—15 new projects in the Senior Companion Program and 20 new projects in the Foster Grandparent Program.

—Funding for quality public relations and information dissemination in connection with RSVP's 30th Anniversary.

—Funding for Programs of National Significance consistent with current law (⅓ of any increase in annual funding).

With regard to any potential funding for demonstration activities in fiscal year 2000, the National Association of Retired and Senior Volunteer Program Directors and the National Association of Foster Grandparent Program Directors request that no funds be allocated for demonstration activities. The National Association of Senior Companion Project Directors requests funding of $2.050 million for demonstration activities involving Senior Companions in order to continue existing demonstration activities, but only after the program line item requests set forth in the testimony are first fulfilled.

With the federal budget in balance as we move into the new millennium, common sense (and congressional budget rules) dictate that we be cost-conscious with our tax dollars—drawing the best return on our investments in Federal programs. Since 1965, FGP, SCP, and RSVP have represented the best in the Federal partnership with local communities, with federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. The evidence supports this claim:

—The Foster Grandparent Program fiscal year 1998 budget of $87.593 million was matched with $34.8 million in cash and in-kind donations from states and local communities in which Foster Grandparents volunteer. This represents a non-federal match of nearly 40 percent—well over the 10 percent local match required by law.

—The Retired and Senior Volunteer Program saw its fiscal year 1997 Federal budget of $35.708 million matched with $42 million in contributions by states and local communities, demonstrating broad support for RSVP across the country. This represents a non-federal match of 118 percent—well over the 30 percent required by law. A recent Westat study found that RSVP volunteer raised $11 million in cash and $114 million in in-kind resources for their volunteer stations.

—And, the Senior Companion Program, with a Federal appropriation of $31.244 million in fiscal year 1997, was supplemented by $19.9 million in cash and in-kind contributions from states and local communities in which Companions volunteer. This represents a match of 64 percent —far in excess of the 10 percent match required by law.

Independent Sector recently estimated the per hour value of volunteer service to be $13.24 per hour. The 120+ million hours of service provided by the nearly 500,000 volunteers serving through RSVP, FGP, and SCP is valued at nearly $1.6 billion, a 10-fold return on the federal investment of $163.240 million in 1998. Obviously, however, the work of our senior volunteers means much more than money. The programs are a lifeline to communities and Americans of all ages.

In 1998, over 27,000 Foster Grandparent volunteers contributed 23.8 million hours of service through 8,400 local agencies, working with children and teenagers who have special needs as well as their families. Last year, 96,000 special needs children, teenagers, and their families daily were supported by the services of Foster Grandparents in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. An estimated 189,500 children receive Foster Grandparent services annually. Foster Grandparents help young people achieve personal independence and self-confidence so that they can learn to overcome their problems and become productive members of society. The annual federal cost for one Foster Grandparent is less than $4.00 per hour.

RSVP volunteers provided over 74 million hours of service in a variety of settings throughout their communities across the country. The total cost of fielding one RSVP volunteer is 48 cents per hour of service. All told, over 450,000 RSVP volunteers serve annually through more than 57,000 public and non-profit local volunteer stations. Sixty-nine percent of RSVP volunteers are over age 70. Volunteers serve through 758 projects sponsored and managed by local non-profit agencies in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. RSVP volunteers provide services that utilize their own talents and interests; they present their

communities with a rich array of options for addressing the full spectrum of community needs. According to a recent study commissioned by the Corporation for National Service, more than 35,000 RSVP volunteers provided over 1,8 million hours of education-related servies to children and youth; 270,000 RSVP volunteers contributed 9.8 million hours of professional or technical support services such as tax preparation assistance or retirement planning, and more than 23 million meals were served at least in part because of RSVP volunteer service.

In 1998, 14,200 Federal and non-federally funded Senior Companions served over 39,000 older adults through 2,900 volunteer stations daily. Senior Companion volunteers contributed over 11 million hours of service to their frail older clients—giving assistance to other adults with physical, mental, or emotional impairments. SCP volunteers serve through 202 programs sponsored and managed by local non-profit agencies in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. Senior Companions help frail older people achieve and maintain the highest possible level of independent living and avoid institutionalization. The average annual cost of nursing home care in the United States exceeds $30,000. The annual federal cost for one Senior Companion is $3,831—less than $4.00 per hour.

For more than three decades, Federally-supported senior volunteers have been touching lives and helping communities in a variety of ways.

Statistics show that FGP, RSVP and SCP focus their resources where they will have the largest impact: FGP on early intervention and literacy activities, SCP on in-home assignments with frail older people at risk of institutionalization, and RSVP on helping their peers, children, and their communities in significant ways. Nationally, 82 percent of the children served by Foster Grandparents are under the age of 12. Recognizing that children's needs are more effectively addressed as early in their lives as possible, 50 percent of these children are age 5 and under. Foster Grandparents work intensively with these very young children to address problems such as developmental delays, illnesses, and literacy at as early an age as possible, before they enter school. One-third of FGP volunteers serve over 8 million hours annually addressing literacy and pre-literacy problems with children who have special needs. Sixty-seven percent of FGP volunteers serve in public and private schools as well as sites which provide early childhood pre-literacy services to very young children, including Head Start.

Twenty-six thousand of the clients served by SCP are 75 or older, and 74 percent of SCP volunteers serve in the homes of clients. It is the 75+ elder population which most often experiences health problems which require institutionalization; SCP prevents institutionalization for these people by focusing on providing one-to-one in-home daily service and companionship to this population. Thirty percent of SCP volunteers provide respite care to families serving as primary care-givers for an elder loved one. Fifty percent of volunteers address chronic care disabilities.

Over ten percent of RSVP volunteers serve in sites which focus on school-age and pre-school age literacy activities, as well as adult literacy. Sixty-four percent of RSVP volunteers provide service to their fellow seniors through congregate meal programs, food banks and kitchens, senior centers, and long term care residential facilities.

We appreciate the goals of the Subcommittee in exercising its best judgment to effect the best use of scarce Federal resources, and as American taxpayers, we endorse your efforts to ensure that tax dollars yield significant impact. We have much evidence that FGP, SCP, and RSVP produce results: numerous and anecdotal stories of lives changed, dollars saved, and lasting good works accomplished in communities across the country.

This evidence is compelling, but we believe that much more is necessary to show that investing federal dollars in FGP, SCP, and RSVP volunteers produces quantifiable, concrete results that significantly impact communities in measurable ways. That is why project directors nationwide, in cooperation with NSSC staff from the Corporation for National Service and with the wholehearted support of the three national Directors Associations, have begun to participate in a new effort, Programming for Impact (PFI).

Through PFI, projects and sites where volunteers serve are cooperating to collect and report data to support the impact our volunteers are having in addressing pressing local community needs. We hope that you will agree that the impact data now coming in truly does document the incredible effect our volunteers are having on communities, and supports your current federal investment in our programs as well as our request for increased funds for fiscal year 2000.

—RSVP volunteers are making the difference at the Illinois Masonic Medical Center. At present, RSVP volunteers play with children and provide translation assistance in the pediatric unit, help to get emergency supplies and calm those in the waiting room, complete paperwork in the trauma unit, assist with bulk

mailings, and provide comfort and support for those in the HIV unit. Jerome Fript, an RSVP volunteer for 9 years, provides cancer tumor registry assistance for the Cancer unit of Illinois Masonic, tracking patients who have been treated for cancer. Mr. Fript volunteers 4 days a week, 5–9 hours a day. As Mr. Fript puts it, "I'm a workaholic. I cannot stay at home with nothing to do. I've played enough golf. I have to get dressed and get out. It's important for me to know that I'm helping others. Just come down once and volunteer—you'll be sold on volunteering."

—After diabetes claimed her leg and confined her to a wheelchair, Florence Styer, 74, of rural Penns Creek, PA, spent her days alone at home, with her telephone as her only link to the outside world. Now, FGP enables Florence—one of 6,000,000 Americans over the age of 60 who are living at or below the poverty level—to volunteer four hours everyday with children like Joseph, a young boy with severe learning disabilities caused by fetal alcohol syndrome. Learning is hard for Joseph. When he is particularly discouraged, he and Florence can be found "walking" together in the hallway or talking quietly with their arms slung around each other's shoulders. Penns Creek Elementary School officials say that, not only is Florence helping Joseph learn to read, but her example is also teaching Joseph a very important life lesson: although he has a disability, he is first and foremost a person capable of doing whatever he sets his mind to. With Florence as his mentor and guide, he will go anywhere he chooses.

—Leona Williams is a 64-year-old widow who has been a senior companion in Milwaukee, Wisconsin for two years. Leona is assigned to five clients and the majority of her clients have mental illness. She provides them with an opportunity they would not normally have. She really makes a difference! Other service providers may get chores done, but do not have four hours to spend with clients. She is with her clients, for them, and stands by them. One of Leona's clients has had chronic anxiety disorders all of her life. When she went off her medication, Leona remained with her during the psychotic break and helped transition her into assisted living quarters. Although she now lives out of Leona's geographic boundaries, Leona travels over 30 miles round trip to visit with her. (And there are thousand more like Leona in the Senior Companion Program.)

As baby boomers age, the "graying of America" is progressing at a phenomenal rate. Yet, only 5 percent of those over 65 years of age live in institutions, and a full 81 percent of the non-institutionalized 65+ population has no limitation in their activities of daily living. According to a U.S. Administration on Aging/Marriott Senior Living Services volunteerism survey, over 41 percent (15.1 million) of the 37.7 million Americans 60 years of age and older performed some sort of volunteer work in the previous year. An additional 37.5 percent (14 million) indicated they would volunteer if they were asked. The message is clear: in spite of the general public's conception of older people as frail and dependent, the aging process is, for most people, a time of wellness when they have both the time and the desire to serve others.

We need more funds to engage more seniors in meeting the pressing needs being expressed by our communities. Your enhanced investment in all three senior volunteer programs now will pay off in the short and long term—savings realized by the value of service rendered to communities across America by senior volunteers; savings realized as additional avenues are provided for more older Americans to be involved in meaningful service opportunities; and savings realized as that involvement keeps older people healthy and independent. Our goal is to expand the Foster Grandparent Program, the Senior Companion Program, and the Retired and Senior Volunteer Program so that they can provide the opportunity for one million Americans to serve by the turn of the century.

Please help us to tap the nation's fastest growing natural resource—our seniors, by supporting a fiscal year 2000 funding level of $48.161 million for the Retired and Senior Volunteer Program (RSVP), $104.560 million for the Foster Grandparent Program, and $43.878 million for the Senior Companion Program.

SUPPLEMENTAL COMMENTS

Reordering priorities in the President's budget

For illustrative purposes only, we would also like to take this opportunity to share with the Subcommittee our specific views on the President's budget, in the event that proposal becomes something of a benchmark for the committee's work.

While we appreciate the support shown by the President's budget for the three programs of the National Senior Service Corps, we feel the priorities set forth in the President's budget for our programs are not entirely appropriate. As we have stated before the Retired and Senior Volunteer Program, Senior Companion Program, and the Foster Grandparent Program do not presently have the funding nec-

essary to fully satisfy the availability of senior volunteers, nor the needs of communities. The President's budget requests $5 million for demonstration activities, while at the same time proposing negligible increases for RSVP, SCP, and FGP. We offer a somewhat different view.

Assuming the President's proposed aggregate fiscal year 2000 funding level for the three National Senior Service Corps programs of $185.032 million, the National Senior Service Corps Directors Associations proposes an alternative distribution of those funds as follows—$98.848 million for the Foster Grandparent Program, $46.518 million for the Retired and Senior Volunteer Program, and $39.666 million for the Senior Companion Program.

This funding allocation assumes the following funding priorities:

—An increase in the volunteer stipend for Foster Grandparents and Senior Companions of $.05 per hour.

—An administrative cost increase of 3 percent in the Foster Grandparent and Senior Companion Programs and 5 percent in RSVP.

—$192,000 in funding for new projects in the Senior Companion Program and Foster Grandparent Program.

—Funding for Programs of National Significance consistent with current law (⅓ of any increase in annual funding).

We believe this funding allocation plan maximizes the number of additional volunteers and volunteer service hours which can be generated for each federal dollar invested, supports existing programs in maintaining their volunteer efforts, and allows for expansion of volunteer efforts in areas of highest community need and in areas currently unserved by FGP, SCP, and RSVP.

In the event the Subcommittee supports the President's aggregate funding level for the National Senior Service Corps programs, we ask that language be included in the committee report accompanying the fiscal year 2000 funding measure which supports and specifies the above allocation priorities for funds requested for fiscal year 2000 and directs the Corporation for National and Community Service to disburse funds for fiscal year 2000 in this manner.

PREPARED STATEMENT OF HOWARD K. AMMERMAN, PH.D.

Once again I am making a plea on behalf of a greater appropriation for the still relatively new and unique United States Institute of Peace. And again I remind you that the creation of this agency was the culmination of about two centuries of efforts in this direction. Furthermore, I again remind you that it is in no official capacity that I do this. Rather, it is a case of having supported lobbying efforts to get the law creating this agency passed in the first place and of having followed the progress of this Institute since its inception. So when the Institute asks for $13 million for fiscal year 2000 my immediate reaction is to say raise this by at least $1 million above the requested amount as a token sum if we are really serious about the basic idea of having such an agency. After all, this comes at a time when the Pentagon is to be given more than it requested.

Perhaps the President of the Institute would not consider it proper to say that the larger figure would in perspective still be "trivial" but I say it is. My background is in economics but not much economics is required to reach such a conclusion. At the risk of sounding conceited it is an insult to my intelligence to accept this trivial sum as an indication of a serious concern on the part of Congress about this approach to the awesome problems of achieving world peace. True not many votes are likely to be lost in doing so little to promote such an agency. But where is the matter of leadership in a concern that history so strongly indicates has been handled by all-too-often ineffectual methods in the past? Something drastically different is necessary, in my opinion. It is to further considerations of both problems and possibilities that I now wish to turn.

Certainly the technological advances of this ending century have been phenomenal. To list them is to be practically certain of forgetting some very significant ones. But, to name a few there is the Salk vaccine, antibiotics, organ transplants, joint replacements and other wonders of medicine and surgery. The automobile and radio were in their infancy at the beginning of this century and the airplane was not yet invented. Then there are television and the computer as examples. Furthermore, the accumulation of knowledge in general has accelerated in recent decades. Certainly these developments have brought great benefits to human kind.

At the same time this century has been characterized as the "worst ever". How have we arrived at this disappointing and shocking conclusion? First, one measure of this sad state is the 110 million wartime casualties, including approximately 2 million children killed in the last fifteen years or so. And this wartime toll is the

smaller of two figures arrived at for this century. So on an overall basis, in the midst of such great "progress" there has been a glaring misdirection in the allocation of attention and resources.

As Basil O'Connor has put it, "How long can we wage war like physical giants and seek peace like intellectual pygmies?" There has been an undue fascination with technology which doesn't wait for social behavior to adjust. And there seems to be more than adequate experience to show that some new mechanical weapon of war or possibly prevention of war will inherently lack the capacity to insure our survival. After all this experience with such weapons covers centuries with great technological changes in the nature of such devices. Rather, with the development of nuclear weapons human kind now has the capacity and the actual weapons to eliminate ourselves from the face of the earth But isn't it logical that lasting peace can come only through changes in human behavior? And despite the efforts over the years of many dedicated workers in research and other areas, can we be said to have waged an effort to achieve peace at all comparable in intensity to that required to develop the atomic bomb, for example? Yet four of the leading scientists in the creation of that bomb felt constrained to point out some very serious implications of its existence so far as human behavior is concerned.

These four physicists wrote a letter to the Secretary of War Henry L. Stimson on August 17, 1945 in response to his request for some technical information regarding this new and radically different weapon, the atomic bomb (which was dropped on Hiroshima and Nagasaki, Japan on August 6 and August 9, 1945, respectively) The technical questions dealt with by these physicists need not concern us here but rather our attention to related matters which they felt obligated to address. First, they pointed out that nuclear weapons far more effective both technically and quantitatively would be developed in the future. These predictions have been markedly fulfilled. Furthermore, they could not foresee development of military countermeasures which would be adequately effective in preventing delivery of nuclear weapons. Nor could they outline a program that would insure hegemony to the United States in coming decades in the field of nuclear weapons. Even if such hegemony were achieved, they could not foresee its protecting us from "terrible destruction".

The scientists went on to say: "We believe that the safety of this nation—as opposed to its ability to inflict damage on an enemy power—cannot be wholly or even primarily in its scientific or technical prowess. It can be based only on making future wars impossible. It is our unanimous and urgent recommendation to you that, despite the present incomplete exploitation of technical possibilities in the field, all steps be taken, all necessary arrangements be made to this one end. . . ." It seems to me that little comfort can be taken in how we as a nation have responded in the past 54 years to this urgent recommendation of these physicists. Can we now do less than make intensive and comprehensive efforts to make up for lost time?

Initially the recommendation of the commission to consider the matter of a governmental peace agency at the national level was to create a "National Peace Academy" as a kind of companion organization of the military academies and there were military professionals who supported the idea. It seems to me that the emergence of a "United States Institute of Peace " really represented a downgrading of the original idea. Somehow the idea of "another campus" by some legislators was considered as going too far. Now it seems to me that the Institute is being pushed in this direction by demands for its educational programs in conflict resolution and peacekeeping as examples. Why should it not be in order to consider an appropriation equivalent to at least one of the military academies? And can a budget of around $13 million be considered suitable to an organization that is to have its own building?

In 1955 a book was published entitled "Towards a Science of Peace", written by psychologist Theodore Lentz. Lentz was a writer of scientific reports on attitude measurement and research. A long-time member of the faculty of Washington University he was founder and Director of the Character Research Association and the Peace Research Laboratory in St. Louis, Missouri. In this book Lentz makes a carefully reasoned plea for the application of the scientific method to this most urgent problem of achieving peace in international relations. In 1972 Lentz followed with a second book, "Towards a Technology of Peace" with the objective being to encourage the development of a technological attitude toward the all-important problem of achieving peace. While observing that the science of peace had moved at "less than an optimum pace" he considered it was still ahead of peace technology.

The idea of a space missile defense program, more often termed "star wars", was first broached by President Reagan in 1983. The reaction of Isaac Asimov, a writer of science fiction and valid science for 49 years, was to fear that perhaps President Reagan didn't know where the line was between the two. Asimov wouldn't say it

couldn't be done but said if it were done it would take perhaps 50 years according to most people with the experience to comment on it. But now, many billions of dollars later, we are still pursuing this perhaps will-o'-the-wisp objective which if achieved would, according to what I can learn, provide a deceptive degree of protection while sending a wrong signal to Russia at the same time. In any case to me it would make more sense, although requiring considerable selling of the idea to the public, to spend perhaps billions pursuing the ideas of Theodore Lentz. To reject the Lentz ideas summarily is in my opinion to downgrade the potential capacities of our collective mentalities. And in no sense and getting back to the matter of economics can I consider it irresponsible to spend billions for what are obviously unconventional ways of proceeding in approaching this problem with which mankind has struggled for centuries.

To me this is a case of rising to perhaps the greatest challenge that mankind can envision. The matters of poverty, health, and environment are inextricably interwoven with the achievement of world peace. The United States Institute of Peace has provided an avenue of hope in its observation, "We are not looking for a revolution in human nature; we are looking for an evolution in human institutions".

PREPARED STATEMENT OF CAROL C. HENDERSON, EXECUTIVE DIRECTOR, WASHINGTON OFFICE, AMERICAN LIBRARY ASSOCIATION

On behalf of the American Library Association, I am submitting this testimony for the hearing record on fiscal year 2000 appropriations for library programs. Founded in 1976, ALA is a nonprofit educational organization of 57,000 librarians in public, school, state, academic and specialized libraries, as well as library supporters, trustees and friends of libraries throughout the country. ALA is dedicated to public access to information and to the improvement of library services for the American people.

LSTA

ALA appreciates the support this Subcommittee has provided for libraries and federal library programs, especially your support of the Library Services and Technology Act state grant program, library services to Native Americans, and funding for the national leadership grant program.

We request your support for fiscal year 2000 funding of $166.2 million for library programs authorized under the Library Services and Technology Act and administered by the Institute of Museum and Library Services.

IASA TITLE VI

In addition, we ask that you fund the Improving America's Schools Act Title VI block grant at least at the level agreed upon by the House last year of $400 million. We have appreciated the subcommittee's funding commitment to Title VI, particularly since it is the only funding possibility for school libraries.

	Fiscal years—		ALA recommendation
	1999	2000 request	
LSTA	$166,175,000	$154,500,000	$166,175,000
IASA VI	375,000,000	.....	400,000,000

INSTITUTE OF MUSEUM AND LIBRARY SERVICES

ALA believes that congressional action in 1996 to locate the Library Services and Technology Act in the Institute of Museum and Library Services was a wise step. The partnership of libraries and museums has been a productive one. While there are differences between these two types of institutions, the synergy at the federal level has been productive in areas that were expected (such as the use of digital technologies to promote greater public accessibility to both library and museum collections) and in unexpected ways (such as illuminating the myriad ways in which museums and libraries were already cooperating at the local level).

The recently resigned Director of IMLS, Diane Frankel, certainly set a high standard for wise leadership and strong professional credentials. She welcomed librarians, was eager to learn about libraries, and made herself available to and accessible to the library community. Moving a program from one agency to another is never easy, but she made a major transition a fairly smooth process. We are con-

fident that IMLS will continue to administer LSTA responsibly and with a very efficient use of federal dollars.

IMPACT OF LIBRARIES

Libraries themselves are also very efficient users of federal dollars. We request funding of LSTA at the total for fiscal year 1999 so they can further demonstrate how efficient they are. No public institution purveys a modest amount of federal stimulus to greater public benefit than libraries. They leverage those funds to attract other dollars, to demonstrate new and innovative methods of providing service that later find local support, and to bring new users into the library for learning, literacy, and the information needed for more productive daily living.

However, the specific benefits from library use may show up only years later: the preschooler whose family library visits make her more ready for reading and learning in school; the parent who sought health information at the library regarding a child's medical condition; the citizen who used federal government information to comment to an agency about pending regulations; the struggling student who spent hours at the library computers and went on to a well-paid technical job; the laid-off worker who honed resume skills and found job opportunities through library databases; the entrepreneur like Mayor Phil Bredesen who upon moving to Nashville, Tennessee started a new business based on library research and used the library as his "roving business office."

No one forces people to use libraries, no one checks why the information they seek is needed, and there is no test to enter or leave. That's the beauty of libraries in a democratic society, but the voluntary nature of use, the cumulative impact of information use over time, and the expectation of user privacy also complicate our ability to assess the impact of libraries.

There are non-intrusive ways for us to begin asking questions such as how library customers use electronic access and how it benefits them, and some early research efforts are under way to measure the impact of technology. ALA's Office for Information Technology Policy is beginning to open discussions with researchers and potential funders to explore ways in which we can get some partial but informative answers to these difficult assessment questions. IMLS and state library agencies are also working on performance indicators for LSTA.

IMPORTANCE OF TECHNOLOGY

A 1998 study sponsored by the ALA Office for Information Technology Policy and the U.S. National Commission on Libraries and Information Science showed that 73 percent of public library buildings have some Internet access, thanks partly to LSTA. However, effective public access is far from complete. Nearly half of these libraries have only one multimedia workstation available to the public, and only one third of these libraries are connecting at speeds greater than 56 kbps. The situation will continue to improve with the e-rate telecommunications discounts. Federal support also helps with the rest of the continuing investment libraries must make in computer hardware and software, electronic content, and training for staff and the public.

Technology has enabled new forms of library outreach to under-served communities such as the cybermobile equipped with traveling technology that has taken to the road in East St. Louis, or the cybermobile in Muncie, Indiana, which travels to senior centers and day care centers and provides equipped space for classes on new technology. As libraries make progress in providing public workstations and training opportunities to the public, more information on specific subjects like health becomes available to a wider public. For example, from July through November of 1998, Illinois libraries conducted 2.1 million searches of electronic databases, compared to 1.1 million during the same months the previous year. See the attachment for examples of the increased availability of electronic materials through statewide library systems.

NATIONAL DIGITAL LIBRARY FOR EDUCATION INITIATIVE

ALA is pleased to see that the budget request for LSTA includes $5 million toward an interagency initiative for digital library materials for educational purposes. This is a large task and a small amount of money. But it could be leveraged to useful effect in a number of ways. Some funds could be used to provide a dependable central registry leading librarians and users to the numerous digitization projects already underway (some of them very useful but specialized or not well known). Some funds could support research to help libraries, museums, and archives meld their different ways of describing collections into seamless access for the user.

Some funds could be used to digitize primary source history material not easily available to students; "virtual": versions would enhance student study of the history of their state. History comes alive through the use of photos, original letters, diaries, local oral and written histories, and other materials, as the Library of Congress's American Memory digitization project has shown. Many more such treasures reside in local libraries.

READING EXCELLENCE ACT

We ask your support of the Administration's request of $286 million for the Reading Excellence Act. Libraries, both public and school, are the other part of the reading equation, providing access to materials for reading practice and enjoyment and librarians who teach information retrieval skills, and are included as partners in the legislation. The National Reading Panel "Progress Report" of February 22, 1999, cites research that "children also need the opportunity to surround themselves with many types of books."

OTHER PROGRAMS

ALA also urges support of adult education and adult literacy programs, and appreciates the strong support of the Administration and Congress for elementary and secondary and higher education programs, as well as educational research and statistics (including the National Library of Education and the 21st Century Community Learning Centers). In addition, we support the request of $1.3 million for the U.S. National Commission on Libraries and Information Science.

Thank you for the opportunity to provide information about federal library programs.

SELECTED EXAMPLES OF LSTA FUNDED PROJECTS UNDER THE STATE GRANT PROGRAM

Alaska.—The Tuzzy Consortium Library is combined Academic/Public library located in Barrow Alaska. It also provides administrative oversight to seven Community/School libraries in the villages Anatuvuk Pass, Atqasuk, Kaktovik, Nuiqsut, Pt. Hope, Pt. Lay and Wainwright. The goal of this LSTA project was to have all seven of the village library technicians meet in Barrow for the weekend and to train them in the use of library resources and effective library management. Participants were introduced to library automation, the Internet, online database searching, and children's programming. Full training sessions were conducted on Friday, Saturday and Sunday.

The objectives were to get better acquainted with village library technicians (VLT), introduce them to Tuzzy Consortium Library's policies and resources, provide them with the basic reference answering techniques and procedures, and train them in the effective use of online resources. As measured by the evaluations of the participants, all four of the objectives were met.

Another LSTA project was directed toward improving statewide access to the materials in the Alaska Resources Library and Information Services (ARLIS) by adding them to the Anchorage Municipal Libraries DRA catalog and circulation system. ARLIS is a consortium of seven state and federal natural resources libraries that formed in fiscal year 1997 as a federal "reinvention project". The seven libraries physically merged collections and staff. Participation in this project allowed them to integrate the catalog and circulation functions.

Anchorage Municipal Libraries (AML) was interested in sharing its technology infrastructure in cost sharing situations which provided favorable pricing for institutional aggregates through formal written agreements. The Alaska Resources Library and Information Services needed an online public catalog/circulation system and was interested in sharing the Anchorage DRA system. As a result of the project, library users statewide have benefited through improved access to resources. Within a keystroke, an ARLIS, AML, or Internet user can see if a book from either institution is checked out or on the shelf.

Arizona.—A $365,000 LSTA project of the Arkansas State Library provides more than 600 public, school, special, and academic libraries with reference, index, and full text articles from thousands of publications via electronic databases. Nursing students find the Health Reference Center database extremely useful, especially those enrolled in new radiology programs. A librarian reported that the students were excited about the new information access: "the full text is a major improvement for us, it provides so many titles that we don't otherwise have."

California.—Current LSTA-supported projects include: "Newsline San Diego" is a telephone-based service that reads local daily newspapers to people with visual and physical disabilities throughout the area, coordinated by San Diego County Library. Carlsbad Public Library is becoming an Info People site ("Internet For People"), a

program providing training, community partnerships, and equipment to establish Internet stations for public use. In nearby National City Public Library, an LSTA-supported community computer center offers 38 hours each week of service for people to take basic computer classes, do word processing and explore the Internet. Three San Francisco Public Library branches have become Info People sites ("Internet For People"). In the nearby Holocaust Center for Northern California library catalog records are being converted to electronic format so that people throughout the nation can learn about the existence of the collection and borrow materials from it.

Hawaii.—The Hawaii State Public Library System (HSPLS) provides library resources to all residents, rural or urban, through a variety of means of public libraries, bookmobiles, and Dial-In Access. Hawaii's distance from mainland United States presents special challenges in accessing information, but by increasing the use of technology and the availability of electronic information, many of these challenges can be met. Currently, using federal LSTA funds, HSPLS is working to upgrade and enhance electronic access to library materials in many different ways: (1) Upgrading the computer systems available in the state's public libraries to enable access to the Internet and the many online resources provided by the library system—an online catalog, magazine and newspaper index, and reference databases; (2) Expanding access to these online resources by providing free Internet access to all state residents simply by dialing into their local public library. This means that Hawaiians can access this information from their schools, businesses, and homes; (3) Installing large-type computer terminals for the Library for the Blind and Physically Handicapped, thereby extending access to service for Hawaii's special populations and integrating them into the mainstream of library services and user groups.

Iowa.—State Library of Iowa uses LSTA to support SILO (State of Iowa Libraries Online) and information databases such as FirstSearch. Because of SILO: students are coming to the public library after school and using SILO. "I even got a thank you note from a student!" one librarian noted, which is "very rare!". Rural libraries that formerly were not able to afford to provide online reference sources are now, through SILO, able to provide everything a "big city library" can. "It makes me feel great to know that we can give our customers what they need".

One librarian said "it feels good to provide accurate information. . . . Sam came in to do a paper and said "I hate C's' He wanted lots of information to get an A". Because the little library could provide FirstSearch, he was well on his way to an A.

"Lots of nontraditional students are using SILO services" reports another librarian. In one school library, the librarian reported that a teacher no longer buses students to a bigger library since the school has access to SILO. "It's nice that the kids can go around the world now" in the library.

Home schooling families are active users of SILO, accessing it at their local public libraries. One patron recommended the local librarian "for sainthood" after getting needed medical information from SILO.

Another patron needed to "locate family members they hadn't talked to in 20 years because the stepfather was dying. We found some of the family members" reports the librarian, using the computer and SILO.

A Rockwell librarian said: "SILO makes a big difference to our library patrons in general. We could never afford or have room for all the books that patrons need. One story I would like to share is about a disabled person who likes to read books on a variety of subjects. We have been able to get this person just about every book that she wants by using SILO. She doesn't have to try to get to another library to get the books. I am so glad we can offer this service".

In other LSTA projects homework centers at Public Library of Des Moines were created as demonstration project with LSTA funds and 80,000 Iowa kids took part in the summer reading program "Rock and Read", sponsored through LSTA.

Mississippi.—The Read for Light project makes any printed material which may be scanned accessible to sight-restricted students and adults in one Tate County School and one Senatobia Public Library facility. Some school children cannot see large-print editions of texts. Many of the 20 percent of county adults age 65+ need size-enhanced reading materials. The $3,000 LSTA grant will provide 27" TV screens, scanners, and computer adapters. Text may be read in type as large as two inches.

Nevada.—The Library Services and Technology Act in Nevada has funded several exciting projects that are furthering information services within the state. Unique Nevada visual resources are being preserved, organized and disseminated in the Nevada State Archives Photograph CD Project. Over 6,000 historic photographs from the State Archives have been scanned and are now being cataloged and loaded into

a database. The end products will be an online database accessible via the Internet and a library of compact disks that will be distributed to the public and academic libraries within the state. Another exciting wave of projects has focused on enhancing services to sight-impaired library patrons. Five public libraries are improving access to electronic information resources by creating information workstations that meet ADA specifications. These public workstations host special software and hardware that will assist special needs patrons in their information.

Pennsylvania.—The James V. Brown Library in Lycoming County has used LSTA funds to install an information kiosk at the Lycoming Mall at the opposite end of the county from the library. The information kiosk connects the patrons at the mall to all of the information resources of the James V. Brown Library including information on education, employment opportunities, government agencies and consumer health. Linda Schramm, coordinator of the Susquehanna Health System's Life office at the mall, says, "We now refer out patients to the kiosk for information on health and wellness. They can find and print articles written from the patient's perspective and take them home."

In Erie, an LSTA funded outreach service of the Erie County Public Library led to the smile on the face of a Bosnian immigrant at a learning center. This middle-aged student of English as a Second Language had witnessed the death of most of his family. Since his arrival in Erie, it had been nearly impossible to elicit a smile from him. One day at the center, while reading a book supplied by the library, he smiled on his own volition, pleased with his progress in learning to read English.

In Philadelphia, people who are unemployed find work via LSTA funded career information materials and software applications at the Free Library of Philadelphia. One client, an unemployed single mother of two, used this workplace center to locate prospective employers and to help her with a resume cover letter. This led her to a position in a children's hospital as an administrative secretary.

South Carolina.—The South Carolina State Library used a significant part of first year funding under the Library Services and Technology Act to initiate a statewide database access project. DISCUS—South Carolina's Virtual Library-provides all South Carolinians with access to an electronic library of essential information resources. These resources are available to every citizen of the state, ensuring equity of access regardless of where people live. The first year DISCUS was available through the Internet to all public libraries and libraries in all institutions of higher education. Three K–12 school districts were also connected. The success of this first year's activities led to the General Assembly appropriating $1.5 million to continue DISCUS and to add all K–12 schools. LSTA funds will now be available to enable public libraries to offer remote access to DISCUS databases.

Texas.—LSTA funds are used to provide public libraries with access without charge to electronic information through the Texas State Electronic Library, a project of the Texas State Library. The electronic resources that are offered without charge to the public libraries in the state are expensive to purchase and to use, and again, the majority of public libraries in Texas do not have the funds to purchase these resources locally. They depend on the Texas State Electronic Library for access to, the Encyclopedia Britannica, Electric Library, the First Search databases, and to both state and federal government resources available through the Internet. Without LSTA funding, the Texas State Electric Library could not afford the price of the information it provides without charge to public libraries and their patrons statewide.

Wisconsin.—Wisconsin Valley Library Service will provide a central site direct Internet connection for 25 member public libraries. This connection will allow the libraries to have a high-speed Internet connection by taking advantage of a state-funded program, TEACH Wisconsin, that makes TI lines available to public libraries at a reduced cost. The LSTA funds will be used for a router at the central site and software to operate the site. This same network also will provide telecommunications access to libraries participating in a systemwide shared automation system and will allow more libraries to join. LSTA funds have been instrumental in providing the seed money to implement and enhance library projects, such as this, that otherwise would not have been possible.

With a $9,975 LSTA grant, the Spooner Memorial Library, in cooperation with five Headstart and childcare centers, is promoting early literacy skills for disadvantaged preschoolers in childcare centers that lack adequate library resources and are unable to transport young students to the public library. The library is establishing rotating collections of children's literature in the childcare centers and working with the staffs of the centers to ensure maximum use and benefit to the children involved.

Washington.—LSTA funds in Washington State have enabled the state library to award five waves of grants for Internet connectivity in many libraries. After an

evaluation and standardization, basic work stations have been installed, software and hardware and training have been provided, as well as follow-up technical assistance. The first wave of grants went to public libraries and the second to some school and tribal libraries. Eighty-seven libraries have received the assistance with another 9–12 coming on-line soon. These grants have leveraged local and private contributions as well as a cooperative spirit and local interest in using the library resources.

PREPARED STATEMENT CAROL PIERSON, PRESIDENT AND CEO, NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

The National Federation of Community Broadcasters (NFCB) submits this statement regarding the fiscal year 2002 appropriation for the Corporation for Public Broadcasting. NFCB is the sole national organization representing 150 community radio stations which provide service in the smallest communities of this country as well as the largest metropolitan areas. Nearly half of our members are rural stations and half are minority controlled stations.

In summary, the points we wish to make to this Subcommittee are that NFCB:

—Supports the CPB request of $350 million for fiscal year 2002

—Requests the Subcommittee to ensure that CPB utilizes digital funds it receives for radio as well as television needs.

—Requests the Subcommittee to ensure that funds for digital conversion be in addition to the PTFP funds that support the on-going needs of public radio and television.

Additionally, NFCB:

—Supports the recent change made by CPB in the formula for distribution of funds for radio stations.

—Supports CPB activities in facilitating programming services to Latino and Native American radio stations.

Community radio fully supports $350 million for the Corporation for Public Broadcasting in fiscal year 2002.—Federal support distributed through the CPB is an essential resource for rural stations and for those stations serving minority communities. These stations provide critical, life-saving information to their listeners. Yet they are often in communities with very small populations and limited economic bases so that the ability of the community to financially support the station is insufficient without federal funds.

In larger towns and cities, sustaining grants from CPB enable community radio stations to provide a reliable source of noncommercial programming about the communities themselves. Local programming is an increasingly rare commodity in a nation that is dominated by national program services and concentrated ownership of the media.

We are very pleased with changes CPB is implementing in the way grants are made to stations. CPB's new policy targets rural radio for significant increases in funding beginning in fiscal year 2000. This recognizes the critical service these stations provide with limited local resources. Funds will also be made available to help extend public radio to places where it is currently not available, and to help stations work together in new and innovative ways. NFCB was privileged to be a part of the consultation process which was very inclusive and constructive.

The following House and Senate Appropriations Committee Report language regarding radio was very much appreciated:

"The Committee urges the CPB in allocating reduced funding to consider the impact of that reduced allocation on rural radio and TV stations, particularly those which are sole service providers, having minimal donor bases, and serve areas with limited cable alternatives." (H. Rpt. 104–209)

"The Committee intends that CPB foster services for unserved or underserved audiences focusing on entities whose primary services are directed at audiences in rural areas and native American audiences. The committee is concerned about the erosion of grants for radio stations serving these communities." (S. Rpt. 105–58)

We commend CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. Satelite Radio Bilingue provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues of particular interest to the Latino population. In the same way, American Indian Radio on Satellite (AIROS) is distributing programming for the Native American stations, arguably the fastest growing group of stations. There are now over 30 stations controlled by and serving Native Americans, primarily on Indian reservations.

CPB plays a very important role for the public and community radio system. They are the convener of discussions on critical issues facing us as a system. They sup-

port research so that we have a better understanding of how we are serving listeners. The Future Fund has provided support for projects that help the system work more efficiently and effectively. Projects have improved fund raising practices, helped groups of stations combine financial functions or underwriting solicitations, and explored ways to use new technologies to improve the programming services that stations are providing.

NFCB thanks the subcommittee for your support of the supplemental appropriation to replace the public radio satellite capacity.—As you know, the timeline for this replacement was suddenly moved up when the Galaxy IV satellite spun out of control. The Public Radio Satellite System is a critical link for community and public radio stations to distribute important national and regional programming. The Satelite and AIROS services use this satellite as do many independent radio producers and the major public radio networks. It is important that $48 million in funding is committed now so that a new agreement can be negotiated by this summer. We support the request for $30.6 million that has been approved by the House with an additional advance funding for fiscal year 2000 of $17.4 million.

Finally, community radio supports funding for conversion to digital broadcasting by public radio and television.—While public television's needs are more immediate, we expect that there will be funds available for radio when a standard for digital radio broadcasting is adopted. However, the television conversion process is already having an impact on public radio stations. As television stations increase the space they need on their towers for two antennas instead of just one, radio stations who rent space on TV towers are losing their leases and being forced to move to other towers—sometimes with very short notice. And the space on other towers is also limited because of the expanded needs of television stations. This situation will only get worse over the next four years as we approach the FCC deadline for television conversion. We would like to see emergency funding to help public radio stations who lose their tower space do the necessary engineering studies and move to new tower locations.

The Administration's proposal of $450 million for digital conversion assumes that all of the funding to the Public Telecommunications Facilities Program (PTFP) in the Department of Commerce will be for digital conversion. This would mean no funding for the current activities of PTFP. In fact, PTFP needs to continue to cover public radio's needs along with the analog needs of television and distance learning projects. We are concerned that the level of funding in the Administration's proposal will not be sufficient to cover the on-going needs of the system and the cost of converting both public television and public radio. We are also concerned that independent producers' conversion needs be addressed in some way so that this important source of programming is not locked out of the system.

We appreciate Congress' direction last year to CPB that it utilize its digital conversion fund for both radio and television and ask that you ensure that the funds are used for both media. Congress stated, with regard to the fiscal year 2001 digital conversion funds:

"The required (digital) conversion will impose enormous costs on both individual stations and the public broadcasting system as a whole. Because television and radio infrastructures are closely linked, the conversion of television to digital will create immediate costs not only for television, *but also for public radio stations* (emphasis added). Therefore, the Committee has included $15,000,000 to assist radio stations and television stations in the conversion to digitalization . . ." (S. Rpt. 105–300)

This is a period of tremendous change. Digital is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the Internet are changing how we define the business we are in; the concentration of ownership in commercial radio makes public radio and particularly community radio, more unique and more important as a local voice than we have ever been. During this time, the role of CPB as a convener of the system becomes even more important. And the funding that it provides will allow the smaller stations to participate along with the larger stations who have more resources, as we move into a new era of communications.

Thank you very much for the support you have provided to public broadcasting in the past and for your consideration of our recommendations regarding community radio.

The NFCB is a twenty four year old grassroots organization which was established by, and continues to be supported by our member stations. Large and small, rural and urban, the NFCB member stations are distinguished by their commitment to local programming and community participation and support. NFCB's 87 Participant members and 103 Associates come from across the United States, from Alaska to Florida; from every major market to the smallest Native American reservation.

While the urban member stations serve communities that include New York, Minneapolis, San Francisco and other major markets, the rural members are often the sole source of local and national daily news and information in their communities. NFCB's membership reflects the true diversity of the American population: 41 percent of the members serve rural communities and 46 percent are minority radio services.

On community radio stations' airwaves examples of localism abound: on KILI in Porcupine, South Dakota you will hear morning drive programs in their Native Lakota language; throughout the California farming areas around Fresno, Radio Bilingue programs five stations targeting low-income farm workers; in Barrow Alaska, on KBRW you will hear the local news and fishing reports in English, and Yupik Eskimo; in Dunmore, West Virginia, you will hear coverage of the local school board and county commission meetings; KABR in Alamo New Mexico serves its small isolated Native American population with programming almost exclusively in Navajo; and on WWOZ you can hear the sounds and culture of New Orleans throughout the day.

In 1949 the first community radio station went on the air. From that day forward, community radio stations have been reliant on their local community for support through listener contributions. Today, many stations are partially funded through the Corporation for Public Broadcasting grant programs. CPB funds represent under 10 percent of the larger stations' budgets, but can represent up to 50 percent of the budget of the smallest rural stations.

PREPARED STATEMENT OF JANE H. WATKINS, PRESIDENT, NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS

The National Association of Foster Grandparent Program Directors (NAFGPD) is pleased to submit testimony in support of fiscal year 2000 funding for the Foster Grandparent Program (FGP), the oldest and best-known of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act of 1973, as amended (DVSA) and administered by the Corporation for National and Community Service.

NAFGPD is a membership-supported professional organization whose roster includes the majority of more than 350 directors who administer Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

FGP: AN OVERVIEW

Established in 1965, the Foster Grandparent Program was the first federally funded, organized program to engage older volunteers in significant service to others. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises nearly 350 programs in every state and the District of Columbia, Puerto Rico, and the Virgin Islands. All of these programs are now primarily based in community volunteer sites—where most special needs children can be found today—and are administered locally through a non-profit organization or agency and an Advisory Council comprised of community citizens dedicated to FGP and its mission. FGP represents the best in the federal partnership with local communities, with federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. There are currently 27,300 Foster Grandparent volunteers who give over 24.6 million hours annually to a total of 189,500 children.

The Foster Grandparent Program is unique for several reasons. We are one of only two volunteer programs in existence that enable seniors living on very limited incomes to serve their communities as volunteers by providing a small non-taxable stipend and other support which allow volunteers to serve at little or no cost to themselves. Our volunteers provide intensive, consistent service—20 hours every week, usually four hours every day. FGP provides intensive pre-service orientation and at least 48 hours of on-going training every year to keep volunteers current and informed on how to work with children who have special needs. And our volunteers provide one-to-one service to their assigned children, exactly what is required to help prepare our nation's neediest children to become self-sufficient adults.

FGP: THE VOLUNTEERS

The Foster Grandparent Program is a versatile, dynamic, and uniquely multi-purpose program. First, we give older Americans who are 60 years of age or older, who are living on incomes less than 125 percent of the poverty level, and who have time

to give the opportunity to volunteer 20 hours every week and use the talents, skills and wisdom they have accumulated over a lifetime to give back to the communities which nurtured them throughout their lives. Seniors in general are not valued or respected in today's society, and low-income seniors are particularly devalued because of their economic status. They are rarely asked by their communities to contribute through volunteering, because they are not traditionally those who participate in community activities. Yet a 1998 Independent Sector report found that seniors in general were approximately four times more likely to volunteer if they were asked.

FGP actively seeks out these low-income seniors. We dare to ask them to serve, to give something back. And we help them to develop the additional skills they may need to function effectively in settings unfamiliar to them, like public schools, hospitals, child care centers, and juvenile detention facilities. We also provide them with on-going training and support throughout their tenure as Foster Grandparents. Through their service, our older volunteers say they feel and stay healthier, that they feel needed and productive. Most importantly, they leave to the next generation a legacy of skills, perspective and knowledge which have been learned the hard way—through experience.

Within budgetary constraints, FGP is doing a good job of engaging older people who are not usually asked to serve and those usually thought of as needing services rather than being able to serve: 69 percent of FGP volunteers are age 70 and older, 53 percent come from various ethnic groups, nearly 40 percent have disabilities, and 45 percent live and serve in rural areas.

—After diabetes claimed her leg and confined her to a wheelchair, Florence Styer, 74, of rural Penns Creek, PA, spent her days alone at home, with her telephone as her only link to the outside world. Now, FGP enables Florence—one of 6,000,000 Americans over the age of 60 who are living at or below the poverty level—to volunteer four hours everyday with children like Joseph, a young boy with severe learning disabilities caused by fetal alcohol syndrome. Learning is hard for Joseph. When he is particularly discouraged, he and Florence can be found "walking" together in the hallway or talking quietly with their arms slung around each other's shoulders. Penns Creek Elementary School officials say that, not only is Florence helping Joseph learn to read, but her example is also teaching Joseph a very important life lesson: although he has a disability, he is first and foremost a person capable of doing whatever he sets his mind to. With Florence as his mentor and guide, he will go anywhere he chooses.

FGP: THE CHILDREN

Second, through our volunteers, the Foster Grandparent Program also provides person to person service to children and youth under the age of 21 who have special or exceptional needs, many of whom face serious—often life-threatening—challenges. With the changing dynamics in family life today, many children with disabilities and special needs lack a consistent, stable adult role model in their lives. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him no matter how many mistakes the child makes, and focuses on the child's successes.

Special needs of children served by Foster Grandparents include AIDS or addiction to crack or other drugs; abuse or neglect; physical, mental, or learning disabilities; speech, or other sensory disabilities; incarceration; terminal illness; teen parenthood. Of the children served, 12 percent are abused or neglected, 22 percent have learning disabilities, and 11 percent have developmental delays. FGP focuses its resources in areas where they will have the most impact: early intervention services and literacy activities. Nationally, 82 percent of the children served by Foster Grandparents are under the age of 12, with 50 percent of these children age 5 or under. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. One-third of FGP volunteers serve over 8 million hours annually addressing literacy and pre-literacy problems with special needs children.

Activities of the FGP volunteers with their assigned children include teaching parenting skills to teen parents; providing physical and emotional support to babies abandoned in hospitals; helping children with developmental, speech, or physical disabilities develop self-help skills; reinforcing reading and mathematics skills; and giving guidance and serving as mentors to incarcerated or other youth.

—In Louisville, KY, Foster Grandparents spend there time mentoring young mothers at the Home of the Innocents Teen Pregnant and Parenting Program. Says one teen mom: "I was always mad at someone or something until Granny came. I sometimes took my anger and frustration out on my young son. Gran-

ny—helped me to understand that everyone has problems and we need to learn to deal with them. She has shared with me things that she went through in her lifetime and that has helped me see that I can handle my life and be a good mother."

FGP: THE VOLUNTEER SITES

Third, the Foster Grandparent Program provides agencies and organizations providing services to special-needs children with a consistent, reliable, invaluable extra pair of hands 20 hours every week to assist in providing these services. Sixty-seven percent of FGP volunteers serve in public and private schools as well as sites which provide early childhood pre-literacy services to very young children, including Head Start. Nationally, Foster Grandparents serve through more than 8,400 public and private non-profit agencies and proprietary health care facilities including public and private schools, child care centers, hospitals, emergency shelters, and correctional facilities.

—As part of NAFGPD's nationwide partnership with the National Head Start Association which has seen a 28 percent increase in the number of Foster Grandparents volunteering in Head Start classrooms since 1997, Foster Grandparents Ida Lewis, 68, and Eliza Price, 77, are trained by speech pathologist Janet King at the Gordon Head Start Center in Lafayette County, MS, to practice speech and language activities with 20 pre-school Head Start children with speech and language impairments severe enough to prevent them from succeeding in a regular school environment. Says Ms. King, "I have observed notable improvement in the children's speech skills. (The Foster Grandparents) are making a world of difference in the skills these children will take with them to kindergarten and hopefully will enable these children to succeed in regular classrooms. The foster grandparents individual sessions have given the speech therapy sessions an added dimension that we never had available to us in the past."

FGP: COST-EFFECTIVE SERVICE

Lastly, the Foster Grandparent Program serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care. Using the Independent Sector's 1998 valuation for one hour of volunteer service ($14.30/hour), the value of the service given by Foster Grandparents annually is $352 million, and represents a 4-fold return on the federal dollars invested in FGP. The annual federal cost for one Foster Grandparent is $3,800—less than $4.00 per hour.

The value local communities place on FGP and its multifaceted services is evidenced by the large amount of cash and inkind donations contributed by communities to support FGP. FGP's fiscal year 1998 federal allocation was matched with over $34 million in non-federal donations from states and local communities in which Foster Grandparents volunteer. This represents a non-federal match of 41 percent, or $.41 for every $1.00 in federal funds invested—well over the 10 percent local match required by law.

THE ADMINISTRATION'S FISCAL YEAR 2000 REQUEST FOR FGP

The rapidly growing number of older people living at poverty-level incomes across the country represents a virtually untapped resource that must be utilized to help address the serious problems of today's children. In order to continue to provide these cost-effective services in even more local communities the Foster Grandparent Program requires more volunteers, and more locally-based programs. We need funding levels which will enable us to keep pace with the ever-increasing number of income eligible seniors—currently 6,000,000, a number which will grow to 13,200,000 by the year 2030—and the countless number of at risk children who will need the one-to-one attention of an older person who has the time and patience to help show them the way to independence and productive adulthood.

Unfortunately, in a budget which requests increases in excess of 25 percent ($110 million) for AmeriCorps and related programs, the Administration has proposed an increase of slightly more than $1.7 million (1.8 percent) for the Foster Grandparent Program, the smallest increase requested for any of the programs administered by the Corporation for National Service. Rather than investing federal funds in FGP, the Administration's request appears to set as a priority a 360 percent (nearly $4.00 million) increase for senior demonstration. The largest, oldest, and best-known of the three senior volunteer programs—the Foster Grandparent Program—is virtually ignored in this budget.

THE ADMINISTRATION'S FISCAL YEAR 2000 REQUEST FOR SENIOR DEMONSTRATION

In the conference report accompanying the fiscal year 1999 appropriations measure, Congress expressed strong concern regarding the Corporation for National Service's practice of using demonstration and regular program dollars to pay non-taxable "stipend" to individuals who do not meet income requirements set by Congress in the DVSA. In spite of Congress' concern, the Administration's budget narrative indicates that the $5.0 million requested for senior demonstration in fiscal year 2000 will be used to continue and expand this practice—to pay non-taxable stipend as an incentive to individuals who do not meet income eligibility requirements set by the DVSA.

NAFGPD, along with the National Association of Retired and Senior Volunteer Program (RSVP) Directors, believes that using funds in this way is wrong, and violates the legislated purpose of the non-taxable stipend paid to FGP (and Senior Companion Program) volunteers: to enable those living on incomes at or below 125 percent of the poverty level to serve 20 hours every week at little or no cost to themselves. Even more basically—as taxpayers ourselves—we believe that using tax dollars to make such payments to people of means simply to motivate them to volunteer is fundamentally wrong. Every dollar appropriated by Congress to be used in this way is a dollar which cannot be used to seek out, engage, train, and enable a low-income senior to contribute to his community as a Foster Grandparent. Before we look to paying stipend to those seniors who already have multiple service opportunities available to them through the nearly 800 Retired and Senior Volunteer Programs nationwide, we must first have sufficient funds to engage every one of the 6,000,000 people currently eligible and able to serve as Foster Grandparents.

To clarify: NAFGPD is not opposed to demonstration efforts which will improve the way we deliver our services, or which will help to test innovative program and volunteer activities. We are opposed to demonstration activities which, if implemented into the existing programs, are designed to change the very nature of FGP. Paying a non-taxable "stipend" to individuals of any income level to volunteer will totally remove the low-income focus of FGP, a focus which has been a fundamental part of FGP's mission since 1965. We are opposed to funding any efforts, through senior demonstration or any other means, which will change this mission.

NAFGPD'S FISCAL YEAR 2000 REQUEST FOR FGP AND SENIOR DEMONSTRATION

Given the growing number of low-income seniors eligible to serve and the staggering number of troubled and challenged children in America today, we believe that the Administration's request does not invest adequately for the future in the Foster Grandparent Program, and actually diverts funds which could be invested in FGP into demonstration activities we cannot and do not support. We ask that you (1) adopt a different fiscal year 2000 funding allocation for FGP, one which will more properly address the important role our programs must play in engaging more of our nation's low-income elders in addressing serious community needs in more communities nationwide; and (2) refrain from appropriating any federal dollars to senior demonstration as long as funds appropriated will be used to pay non-taxable stipend to individuals not meeting income requirements set by Congress.

NAFGPD's fiscal year 2000 request is as follows:

[In millions of dollars]

Foster Grandparent Program	104.560
Senior Demonstration	

We also request that the Committee include report language accompanying the fiscal year 2000 funding measure which supports and specifies the following allocation priorities for use of the fiscal year 2000 increases, and directs the Corporation for National Service to disburse funds in the following manner:

1. For the Foster Grandparent and Senior Companion Programs, increase the stipend which enables low income volunteers to serve from $2.55/hour to $2.60/hour. Funds should be available to pay for the additional $.05 per hour for non-federally funded volunteers for one year. The last stipend increase—from $2.45/hour to $2.55/hour—occurred in January, 1998.

2. Award an administrative cost increase of 3 percent to each existing Foster Grandparent Program in order to maintain quality and sustain the work already being done by programs.

3. In accordance with the Domestic Volunteer Service Act (DVSA), use ⅓ of the increase over the fiscal year 1999 level to fund Program of National Significance (PNS) expansion grants to allow existing FGP programs to expand the number of

volunteers serving in areas of critical need as identified by Congress in the DVSA, and not limited to America Reads activities.

Finally: Begin 20 new Foster Grandparent Program projects in geographic areas currently unserved.

All told, this funding proposal will generate opportunities for more than 1,900 new low-income senior volunteers contributing in excess of 2.0 million hours of service annually to more than 11,600 additional children with special and exceptional needs. In addition, 20 more communities will receive the multifaceted services of FGP, a small step—but an important step—toward NAFGPD's goal of beginning 100 new Foster Grandparent Programs nationwide over the next five years.

A recent New York Times article (March 21, 1999) on volunteers and retirement stated that ". . . Thousands of older people are on the waiting list for the Foster Grandparent program, in which 25,000 older adults whose income is below the poverty line receive a small stipend for volunteering 20 hours a week to be grandparents for disabled or disadvantaged youngsters. Many young people need mentors and foster grandparents, but lack of money precludes more participation." Our experiences, especially with long waiting lists of seniors waiting to serve, strongly support this statement. In addition, in communities which already have a Foster Grandparent Program, unfilled requests from local organizations for more Foster Grandparents are the rule, not the exception.. And when Congress provided funds for 25 new Foster Grandparent Programs in fiscal year 1998—the first new programs in 18 years—125 high-quality applications were submitted by local community organizations nationwide.

Although it is true that the population of better-educated, wealthier seniors will increase as the baby boomers age, a 1998 AARP survey conducted by Roper Starch Worldwide indicated a "sea change" in retirement patterns: the majority of these "boomers" intend to continue to keep their jobs and never retire from work. The 1998 Independent Sector study showed that seniors who are still working are more likely to volunteer on an informal basis than to volunteer in a program like FGP, which requires 20 hours of service every week. It will be the "boomers" who have not acquired the skills needed to keep their jobs as they age—primarily those who have had low paying jobs and those who have been downsized to make room for technological advances—who will be available to volunteer every day, who will need FGP to provide them with opportunities to stay active and contribute.

The message is clear: (1) the population of low-income seniors available to volunteer 20 hours every week is increasing; (2) communities need and want more Foster Grandparent volunteers; and (3) communities want more Foster Grandparent Programs.

FGP needs more funds to serve more communities and engage more low-income seniors in meeting the pressing needs being expressed nationwide. Your enhanced investment in FGP now will pay off in the short and long term—savings realized by local communities, savings realized as additional opportunities are provided for more older, low-income Americans to stay active in their communities, and savings realized as that involvement helps older people to stay healthy and independent and children with special needs to become contributing members of society.

Please help us tap one of the nation's only increasing natural resources—our low-income seniors—by supporting a total fiscal year 2000 appropriation of $104.560 million for the Foster Grandparent Program, without diverting any precious and scarce funds to senior demonstration for fiscal year 2000.

MULTIPLE AGENCIES

PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates this opportunity to comment on fiscal year (FY) 2000 appropriations for nursing education, nursing research and workforce programs. ANA is the only full-service professional organization representing the nation's 2.6 million registered nurses, including staff nurses, nurse practitioners, clinical nurse specialists, certified nurse midwives and certified registered nurse anesthetists through its 53 state and territorial nurses associations.

We gratefully acknowledge this Subcommittee's support for nursing education and research. You have continued to recognize the importance of nurses in health care delivery and have funded programs for nursing education and innovative practice models. Most recently, the American Organization of Nurses Executives (AONE) released a survey on nursing staff shortages. ANA and the Division of Nursing collaborated with AONE in the survey development and review of the data. The survey confirms what ANA has been saying about the present status of demand for nursing

services and the increased need for specialist nurses. Therefore, we believe that our shared goal of ensuring the nation of an adequate supply of well-educated nurses, to meet the increasing demands of our rapidly changing health care system, will reaffirm the need for increased funding of these programs. Today, we offer our professional recommendations for federal funding of nursing education, nursing research and workforce programs.

DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS NURSE EDUCATION ACT

Advanced practice nurses—registered nurses with education and clinical experience generally at a master's degree level—are providing primary care services in place of physicians or are providing an expanded type of primary care, either as nurse practitioners, certified nurse midwives or clinical nurse specialists. Due to unprecedented changes in our health care delivery system and the changing demographics and complexity of care, nurse practitioners will be in increasing demand and the nurse education system will be stretched to provide first-quality training for them. These changes call for the fullest utilization possible of the multi-disciplinary providers who care for patients and families in an ever-increasing array of settings: hospitals, subacute care facilities, rehabilitation facilities, long term care facilities, schools and universities, workplaces and communities.

Federal support for nursing education in Title VIII of the Public Health Service Act (PHSA) is unduplicated and essential to achieve future goals for the public's health. Last year, Congress reauthorized these programs by enacting "The Health Professions Partnership Act of 1998" Public Law 105–392. This law gives the Secretary of Health and Human Services broad discretion to determine which projects to fund, with priority given to projects which would substantially benefit rural or underserved populations, including public health departments. Under Public Law 105–392, the improved Nurse Education Act (NEA), the Division of Nursing has the needed flexibility to focus on curriculum development and other programs to address the changing health care environment and assist in the preparation of more nurses who are able to function where there is a greater demand. NEA will better address the need for increasing the numbers of minority nurses available to provide culturally competent, linguistically appropriate health care services to underserved communities by providing funding to support projects that would increase nursing education opportunities for individuals from disadvantaged backgrounds. These nurses would then be better prepared to assist these populations in changing the way they access our health care system, and in helping these patients understand the advantages of developing relationships with primary providers. By itself, the behavior change from accessing health care services through emergency departments, to one in which the consumer routinely seeks care through a primary provider, decreases health care costs exponentially.

With new legislation in place, it is crucial that the Division of Nursing be provided with the funding necessary to effectively implement these program changes. For fiscal year 1999, due to the work of this Subcommittee, the Nurse Education Act was funded at $67.8 million. This Subcommittee believed this was a sound investment in our country's health care. For fiscal year 2000, we are requesting an increase in funding of 10 percent over fiscal year 1999 to fund the Nurse Education Act programs at approximately $74 million. Additionally, ANA does not support the Administration's proposed reduced funding level for Title VII of the Public Health Service Act at a time when continued shortages of primary care providers still exist in certain parts of the country.

The reauthorization consolidated the NEA into three new authorities. These authorities are as follows:

Advanced education nurses.—Advanced education nurses are registered nurses trained in advanced degree programs, generally at a master's degree level. They provide primary care in lieu of physicians or provide an expanded type of primary care. This category includes nurse practitioners, nurse midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, public health nurses and other nurses as determined by the Secretary of the Department of Health and Human Services. Traineeships for advanced nursing education will be provided under this category.

Programs to increase workforce diversity.—Both overutilization of costly emergency services and decreased access to primary care have been associated with a low representation of minority health care providers. This reauthorization provides for increased flexibility in the use of funds to enhance diversity in nursing education and practice. It will support projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities. Some support will be provided through student scholarships or stipends and can be used for pre-entry preparation and retention activities. Continued funding

for programs that access this type of funding is dependent on demonstrated outcomes.

Projects to strengthen the capacity of basic nursing education.—Funding under this category would assist programs toward expanding basic nurse education, thereby enhancing the basic nursing workforce. Priority areas identified include: skills development for practice in organized health care systems; nursing practice arrangements, care for underserved populations and other high risk groups; cultural competency; baccalaureate enrollment; career mobility; informatics education, including distance learning methodologies and other areas as needed. Nurse Managed clinics would be included under this category. A recent New York Times article reported that many of the nation's hospitals are experiencing a shortage of registered nurses, especially the specialized, highly trained nurses who staff operating rooms, emergency rooms, intensive care units and pediatric wards for high risk babies.

Nurse loan repayment (section 836)

This program provides for up to 85 percent repayment of student loans for nurses who agree to a service payback in nursing shortage areas. We recommend funding at $2.3 million.

National Institute of Nursing Research (NINR)

The second funding priority for nursing is funding for the NINR, on the campus of the National Institutes of Health (NIH). Again we applaud this Subcommittee's commitment to advancing behavioral science research. Nursing research is an integral part of the effectiveness of nursing care. The NINR provides the knowledge base for practice of 2.6 million registered nurses. Advances in nursing care arising from nursing and other biomedical research improves the quality of patient care and has shown excellent progress in reducing health care costs and health care demands. Research programs supported by the NINR address a number of critical public health and patient care questions. The research is driven by real and immediate problems encountered by patients and families. Study results offer the clear prospect of improving health , reducing morbidity and mortality, and lowering costs and demand for health care. Increased funding would enable an NINR initiative to develop and test interventions to help children with asthma and their parents prevent asthma attacks, monitor airway inflammation, and manage daily routines of care at home and at school. An increase in funding would also allow NINR to establish an initiative consistent with the recommendations of the Congressionally-established Diabetes Research Working Group. The specific focus would be to intensify clinical behavioral research to improve both patient adherence to diabetes treatment and quality of life. These interventions will result in lifestyle behaviors which will effectively reduce the risk of developing complications of diabetes or delay their onset. While we support the Administration's proposed 2 percent increase above fiscal year 1999 funding of $69.8 million for this program, we recommend a $20.9 million increase to fund NINR at $90.7 million.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Clinical Training Program The SAMHSA Clinical Training Program has been a major source of the nation's mental health clinical training funds, and is a source of funding for ANA's Minority Fellowship Project (MFP). The funding is allocated through SAMHSA to the minority mental health training programs in Nursing, Psychology, Social Work and Psychiatry. The MFP graduates have an outstanding record of public service to minority and indigent communities.

MFP graduates receive doctoral degrees and as clinicians, work in high risk urban and rural areas providing care to children and families who are victims of violence, HIV/AIDS, and substance abuse as well as the mentally ill. These nurses work in community based clinics and outreach programs and often are the primary care providers for indigent clients who might otherwise go without needed mental health services. In addition, MFP graduates generate research on minority mental health services, treatments and client outcomes. Culturally appropriate research helps us to identify ways to provide services faster and to more people, ultimately improving health care outcomes and reducing health care costs. This works to change the poor health outcomes and high risk health status that continues to plague minority communities. These graduates also work as teachers in schools of nursing that serve minority students, serving as role models and providing leadership to future nurses. We believe this program is a good investment in reducing mental health care costs and recommend funding of $2.0 million for fiscal year 2000 for the SAMHSA Clinical Training program.

AIDS education and training centers (AETC)

The AETC program in the Bureau of Health Professions at the Health Resources and Services Administration provides specialized training for health care personnel who care for patients with AIDS. Emerging and evolving scientific information with profound impact on individual and public health requires a ready network for information dissemination and technology transfer. AETCs reduce care costs by increasing treatment and care expertise which serves to ease the suffering of families and communities. It is for this reason that we recommend a funding level of $25 million for fiscal year 2000 for the AETCs.

The National Institutes for Occupational Safety and Health (NIOSH)

NIOSH is the only federal agency with the mission to conduct research and develop practical solutions to prevent work injury and illness. NIOSH played a key scientific role in the development of the blood borne pathogens standard which provides significant protection to front-line health care providers from possible exposure to blood borne pathogens, such as HIV, Hepatitis-B and Hepatitis-C. In addition, NIOSH funds Educational Resource Centers. These multi-disciplinary, university based occupational health and safety training and research centers are the primary vehicle for the development and training of a corps of trained occupational health nurses and other safety professionals. We support the Administration's recommended fiscal year 2000 funding of $212 million for NIOSH.

OTHER WORKFORCE FUNDING RECOMMENDATIONS

As an advocate for the economic and general welfare of registered nurses, the American Nurses Association also recommends appropriate funding for the Department of Labor and related agencies that serve to ensure a safe and fair workplace. ANA believes the work done by the Bureau of Labor Statistics, with respect to the ongoing collection and analysis of employment and economic data, is necessary for tracking changing economic conditions and essential to making workforce projections. We urge your support of the Bureau.

National Labor Relations Board (NLRB)

ANA is concerned about the ability of the NLRB to meet its statutory responsibility of enforcing and interpreting the National Labor Relations Act (NLRA). Potential delays in the processing of complaints and holding representation elections may jeopardize the progress in employee and employer relations. ANA considers this a core independent agency function that must be preserved. We support the Administration's recommended fiscal year 2000 funding of $210 million for the NLRB.

Occupational Safety and Health Administration (OSHA)

The rapid restructuring of the health industry has increased, and in some cases exacerbated, the risk of exposure to illness and injury for nurses and other health care workers. Hospitals and HMOs are downsizing both to cut costs and be competitive in the health care marketplace. These economic pressures have led to a reduction in the number of registered nurses providing care at the bedside. The remaining nurses in these acute care settings have to work harder and take care of more and sicker patients than ever before. The nurses themselves are sustaining more frequent incidences of injury and illness. According to the Bureau of Labor Statistics, in 1993, back and shoulder injuries accounted for 50 percent of the 31,422 injuries and illnesses that kept registered nurses away from work. Overall, lifting was specified as the cause of 26 percent of all registered nurse injuries. ANA is concerned about the increased occupational risks in nursing and their negative effect on nurses today and the future of this profession.

ANA continues to be concerned about the strength of the Office of Occupational Health Nursing and its parity with similar offices. Occupational health nurses are the largest group of health care providers at the nation's work sites. As such, they are uniquely qualified to assess the practical realities of work sites and related regulatory activities. This office must be fully staffed in order to accomplish its critical task of linking the ongoing work of occupational safety and health nurses to OSHA. We support the Administration's recommendation for fiscal year 2000 funding of $388 million for OSHA.

CONCLUSION

We appreciate the opportunity to comment on funding for nursing education, research and workforce programs. We thank you for your continued support and look forward to working with you as you proceed through the appropriations process.

PREPARED STATEMENT OF STANLEY B. PECK, EXECUTIVE DIRECTOR, AMERICAN DENTAL HYGIENISTS' ASSOCIATION

The American Dental Hygienists' Association (ADHA) is pleased to submit its recommendations regarding fiscal year 2000 appropriations for the Department of Health and Human Services (HHS) and the Department of Labor (DOL). ADHA is the largest national organization representing the professional interests of the more than 100,000 registered dental hygienists (RDH) across the country. Dental hygienists are preventive oral health professionals, licensed in dental hygiene, who provide primary educational, clinical and therapeutic services supporting total health through the promotion of optimal oral health.

THE NATION'S ORAL HEALTH

Oral health is fundamental to total health. As former Surgeon General C. Everett Koop noted, "if you don't have oral health, you're not healthy." Despite recent advances in preventing oral disease and maintaining oral health, oral diseases still afflict 95 percent of all Americans. Oral Health America/America's Fund for Dental Health reports that 20 million workdays and 9 million school days are lost annually because of oral health problems.

According to Public Health Reports, dental caries is the single most common disease of childhood which is neither self limiting, like the common cold, nor amenable to a course of antibiotics, like an ear infection. Dental caries occur 5–8 times more commonly than asthma, the second most common disease of childhood. Despite well-noted reductions in decay prevalence, tooth decay—which is an infectious transmissible disease—still affects more than half of all children by second grade.

COST-SAVINGS ASSOCIATED WITH PREVENTIVE ORAL HEALTH CARE

In contrast to most medical conditions, the three most common oral diseases—dental caries (tooth decay), gingivitis and periodontitis (gum and bone disease)—are proven to be preventable with the provision of regular oral health care. This proven ability translates into huge cost savings. Each $1 spent on preventive oral health care yields $8—$50 in savings. Because of this, increased access to the preventive oral health services provided by dental hygienists will likely result in decreased oral health care costs per capita and, more importantly, improvements in the nation's oral and total health.

DENTAL CARIES (TOOTH DECAY) IS AN INFECTIOUS TRANSMISSIBLE DISEASE

Dental caries, popularly knows as tooth decay, is an infectious transmissible disease. Research shows that the presence of bacteria known as streptococcus mutans leads to dental caries in children. This decay causing bacteria is typically transferred from primary caregivers to young children between 22–26 months of age.

The impact of oral disease extends well beyond the oral cavity. Research shows that the presence of periodontal or gum disease is linked to such life threatening conditions as cardiovascular disease, stroke, and pre-term deliveries. People suffering from gum disease are two or three times as likely to suffer from coronary artery disease than those without periodontal problems. Pregnant women with periodontal disease are seven times more likely to deliver pre-term low birthweight infants. This is because periodontitis is a bacterial infection and bacterial infection accelerates the production of labor inducing fluids, leading to the premature onset of labor. To further our understanding of the links between oral disease and systemic disease, research at the National Institute of Dental and Craniofacial Research (NIDCR) is vital.

SURGEON GENERAL'S REPORT ON ORAL HEALTH

The first-ever Surgeon General's Report on Oral Health is expected to be published this year. The Report is currently divided into various sections, including: what is oral health; what is the status of oral health in America; what are the implications of oral health status; how are oral health and oral diseases and conditions managed; and what can be done to enhance oral health throughout life stages. Publication of this Report recognizes the importance of oral health to total health.

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

The National Institute of Dental and Craniofacial Research (NIDCR) is one of the thirteen major biomedical research institutions within the National Institutes of Health. NIDCR has helped to revolutionize our knowledge of preventive health care by identifying the causes of preventable oral diseases and the appropriate strategies

to combat them. One of the most successful public health projects in history—water fluoridation—was launched more than 50 years ago as a result of research conducted by NIDCR's very first director. More recently, through NIDCR sponsored research we have:

—showed unequivocally that dental caries and periodontitis are bacterial infectious diseases;
—made progress toward a vaccine against dental caries and other oral infections;
—improved adhesive sealants to protect teeth from the ravages of dental caries;
—discovered biomarkers associated with tumor growth and tumor suppression associated with oral cancer;
—pinpointed antibodies in saliva that are critical to maintenance of oral tissue; and
—demonstrated the importance of education and promotion activities in assuring good oral health.

NIDCR's work in dental research has resulted in better oral health for the nation and has helped curb increases in oral health care costs. Accordingly, ADHA requests that the Subcommittee appropriate $277 million in fiscal year 2000 funding for NIDCR. This funding level will not only support NIDCR's many important projects but will help hold the line on increases in oral health care costs.

TITLE VII OF THE PUBLIC HEALTH SERVICE ACT

ADHA joins the Association of Schools of Allied Health Professions and others in calling for $8 million for "Allied Health and Other Disciplines." Although allied health disciplines constitute approximately 60 percent of the health care work force, fiscal year 1999 spending on allied health project grants, for example, was only $4.980 million.

SCHOLARSHIPS FOR DISADVANTAGED STUDENTS

ADHA supports full funding for programs such as Scholarships for Disadvantaged Students which provides grants to health professions schools to assist in providing scholarships to individuals from disadvantaged backgrounds. This program was created to address serious problems in the delivery of health care to disadvantaged minorities. Full funding is critical to efforts to recruit more minorities into dental hygiene and other allied health professions.

CENTERS FOR DISEASE CONTROL

The Division of Oral Health within the National Center for Chronic Disease and Health Promotion Prevention funded through the Centers for Disease Control (CDC) is a key support mechanism for state dental health programs. As a national leader in dental disease control and prevention, the Division of Oral Health provides consultation, training, promotional and educational support, disease surveillance, and other technical services to state and local governments and other professional, educational and citizen organizations. ADHA requests that the Division of Oral Health be funded at $10 million.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

ADHA urges support for the Agency for Health Care Policy and Research (AHCPR) at $225 million. ADHA further urges the Subcommittee to direct AHCPR to develop an oral health research agenda focusing on preventive oral health care effectiveness, quality and outcomes measures for the preventive oral health services provided by dental hygienists. ADHA also encourages the Subcommittee to insist that the recommendations of the National Commission on Allied Health be fulfilled, including the recommendation that Congress allocate $5 million to AHCPR each year for five years to conduct outcomes-based allied health research projects with near-term application to clinical practice.

DEPARTMENT OF LABOR OCCUPATIONAL SAFETY AND HEALTH ADMINISTRATION

ADHA believes that the Occupational Safety and Health Administration (OSHA) has an important role to play in promoting employee safety in the workplace. ADHA has historically supported OSHA's work with regard to the dental workplace, including OSHA's bloodborne pathogens standard, which governs employers' obligations concerning occupational exposure to the Hepatitis-B Virus (HBV), Human Immunodeficiency Virus (HIV) and other bloodborne pathogens, and OSHA's hazard communication standard, which requires the development of material safety data sheets (MSDSs) for hazardous chemicals so that workers know the hazards and identities of the chemicals they are exposed to while working, as well as the measures they

can take to protect themselves. More recently ADHA has assisted OSHA in the development of an ergonomic standard. ADHA believes—and the scientific literature supports—the work relatedness of ergonomic disorders, such as carpal tunnel syndrome, among dental hygienists. ADHA urges the Subcommittee to appropriate monies such that OSHA will be able to promote employee safety in the workplace, including the dental hygiene workplace.

CONCLUSION

ADHA encourages the Subcommittee to continue its support of preventive health programs and preventive health professionals as the most responsible method for long-range reductions in national health care expenditures. ADHA is committed to working with this Subcommittee—and all Members of Congress—to improve the nation's oral health. We appreciate the opportunity to submit our views.

PREPARED STATEMENT OF ROBERT M. TOBIAS, NATIONAL PRESIDENT, NATIONAL TREASURY EMPLOYEES UNION

Chairman Specter, Members of the Subcommittee: My name is Robert M. Tobias and I am the National President of the National Treasury Employees Union (NTEU). On behalf of the more than 155,000 federal employees represented by NTEU across the government, I appreciate this opportunity to share NTEU's views on the fiscal year 2000 funding needs for agencies within the Department of Health and Human Services (HHS) and the Social Security Administration (SSA).

NTEU is proud to represent employees in the following HHS divisions: Administration for Children and Families, Administration on Aging, Agency for Health Care Policy and Research, Health Resources and Services Administration, National Center for Health Statistics, Office for Civil Rights, Office of the Secretary, Program Support Center, and the Substance Abuse and Mental Health Services Administration. In addition, NTEU represents employees in SSA's Office of Hearings and Appeals.

As the Chairman and Members of the Subcommittee already know too well, there is scarcely an agency within the federal government today that has been appropriately funded during the last several years. Discretionary spending cuts have come, not with the precision of a scalpel, but rather with the force on an axe. Public servants pride themselves on offering first class service to those who depend on the programs administered by their agencies. And they have continued to carry out their agencies' missions to the best of their abilities, but without additional resources, there is no question that programs the public depends on will begin to suffer. There is simply nowhere left to cut corners.

With the current booming economy and budget surpluses projected for the near future, there is no economic rationale for continuing to bleed these agencies dry. Federal employees have done more than their share in creating the budget surplus we have today. Current and projected budget surpluses are the result of the sacrifices made by federal employees in terms of pay and benefit cuts and the squeeze agencies have experienced in terms of both a lack of funding for program administration, and restricted training opportunities for employees.

Few would dispute the fact that federal employees helped achieve our current balanced federal budget. These same federal employees now want to share in the strong economy they helped create. For agencies funded under this appropriations measure, that means program direction funding levels reflective of the importance of the programs. Moreover, it means ensuring that agencies have the resources to provide training to employees to enable them to fulfill their agencies' missions to the best of their abilities.

NTEU is deeply concerned that the House and Senate versions of the fiscal year 2000 Budget Resolution appear to ignore current agency funding problems and require further unrealistic cuts. The discretionary spending limits included in these resolutions are at least $10 billion below fiscal year 1999 levels. According to the Congressional Budget Office, these resolutions could result in cuts in federal programs of between $9 and $25 billion dollars. Spending cuts of this magnitude would wreak havoc with federal programs and could result in massive layoffs of federal employees. Furthermore, as much as NTEU appreciates this opportunity to discuss federal agency funding needs, I must also tell you that NTEU will aggressively oppose this and any other appropriations measure that fails to provide realistic funding for the federal government and its employees.

The Administration's fiscal year 2000 budget addresses federal agency funding needs in a much more realistic fashion than the pending Budget Resolutions. For the Administration for Children and Families (ACF), the President's budget request

includes $150 million for program direction. This request represents an increase of $6 million over ACF's fiscal year 1999 funding and will allow the agency to continue its vital travel and monitoring activities. ACF has primary responsibility for the overseeing welfare reform and for administering Head Start, child support, foster care and adoption programs. Past funding reductions have hampered ACF's ability to fulfill its mission and I implore this Subcommittee to insure that, at a minimum, the President's budget request in this area is adopted.

For the Administration on Aging (AOA), the President's budget recommends $17 million in program administration funds, an increase of $2 million over the agency's fiscal year 1999 level. As you know, AOA administers the Older Americans Act and operates the Home Delivered Meals Program. This appropriation will help support the delivery of approximately 146 million meals in fiscal year 2000 and enable high risk individuals to remain in their homes and communities. With 45 million Americans over 60 years of age, the worthwhile work of AOA is increasingly necessary. By the year 2030, the Census Bureau predicts these numbers will almost double to 88 million Americans over the age of 60. Moreover, to the extent appropriations for AOA assist older Americans in remaining out of nursing home facilities, the savings to the federal government in terms of Medicare and Medicaid expenditures is dramatic. AOA and its important programs deserve to be fully funded in fiscal year 2000.

The Agency for Health Care Policy and Research (AHCPR) is slated to receive $2 million in program support funding in fiscal year 2000—the same as the agency received in fiscal year 1999. AHCPR helps turn knowledge gained through health care research into measurable improvements in the American health care system.

For the Health Resources and Services Administration (HRSA), $128 million in program management funds has been requested. This represents a small increase of $2 million over the agency's fiscal year 1999 funding level and is the minimum acceptable to continue HRSA's important mission. In addition to improving access to health care for those Americans who are medically underserved, HRSA's mission includes an emphasis on programs that seek to expand health care options for pregnant women and their children.

NTEU also wants to bring to your attention the important work of the National Center for Health Statistics (NCHS). This agency, within the Centers for Disease Control and Prevention, operates major statistical systems that track changes in health and health care. NCHS assesses the effectiveness of public health programs and identifies health problems and disease patterns across the United States. The President's request for a $15 million increase over the agency's fiscal year 1999 appropriation of $95 million reflects the critical work undertaken by this agency.

The mission of HHS's Office of Civil Rights (OCR) includes enforcing civil rights statutes that prohibit discrimination in federally assisted health care and social services programs and coordinating government-wide enforcement of the Age Discrimination Act. In recognition of its important work, the Administration has requested $22 million for OCR fiscal year 2000, a $1 million increase over the fiscal year 1999 funding level. Despite OCR's enormous areas of responsibility, past appropriations levels have not kept pace with the agency's workload and staffing needs. It is critical that, at a minimum, the Administration's request be adopted.

Employees in the Office of the Secretary support those activities associated with the Secretary's roles as chief policy officer and general manager of the Department. For fiscal year 2000, the Administration has requested $192 million in general departmental management funding, an increase of $7 million over 1999.

The Program Support Center (PSC) was formed in 1996 by combining offices that had formerly reported to the Office of the Secretary and the Office of the Assistant Secretary for Health. PSC's formation was designed to minimize any duplication of functions and provide administrative, human resource and financial management services to components of HHS and other federal agencies. The fiscal year 2000 request for PSC is $282 million, an $11 million increase over the Center's 1999 funding level.

The Administration's fiscal year 2000 funding request for program management at the Substance Abuse and Mental Health Services Administration (SAMHSA), is $58 million, a $5 million increase over the agency's fiscal year 1999 funding. This increase is necessary if SAMHSA is to continue to strive to provide access and reduce barriers to mental health services. In addition, the agency's critical work in the areas of chronic drug use and substance abuse necessitate at least this $5 million increase in program funds. Lack of adequate funding in past years has resulted in forgone employee training and prevented project officers from travelling to oversee and monitor existing grant projects, areas critical to SAMHSA's mission.

NTEU also represents employees in the Office of Hearings and Appeals (OHA) of the Social Security Administration (SSA). I want to bring to this Committee's atten-

tion the significant reorganization underway at OHA. This fast-track reorganization is designed to lead to hearings process improvements. NTEU is monitoring this reorganization, which, if not carefully crafted and implemented, could adversely affect hearing office operations.

As the Chairman may know, many OHA attorneys are continuing to participate in the remarkably successful Senior Attorney Program. Under this innovative approach, senior attorneys review those disability cases most likely to result in a fully favorable decision before they are assigned to the disability que. Deserving claimants receive a decision in approximately 120 days instead of waiting an average of 320 days for their cases to be heard through normal OHA channels.

Although the massive increase in the disability backlog that OHA experienced in the early 90's has been contained and substantially reversed through programs such as the Senior Attorney Program, work remains to be done in this area. The beauty of the Senior Attorney Program is that it utilizes existing agency resources to the best advantage. Although NTEU has brought its concerns to both the agency's and Congress' attention, SSA has already taken steps to curtail the program. While the agency is developing other innovative programs for improving the disability process, NTEU urges SSA to continue the Senior Attorney Program without further reduction until a permanent, equally successful replacement program has been successfully implemented. If and when concerns in this area arise, NTEU will share them with this committee.

Mr. Chairman, thank you again for this opportunity to share our views on the fiscal year 2000 needs of the agencies within the jurisdiction of your Committee.

PREPARED JOINT STATEMENT OF THE NATIONAL ALLIANCE TO END HOMELESSNESS; NATIONAL COALITION FOR THE HOMELESS; NATIONAL COALITION FOR HOMELESS VETERANS; NATIONAL HEALTH CARE FOR THE HOMELESS COUNCIL; NATIONAL LAW CENTER ON HOMELESSNESS AND POVERTY; AND THE NATIONAL NETWORK FOR YOUTH

SUMMARY

Appropriate at least $1.025 billion for Consolidated Health Centers, including at least $88 million for the Health Care for the Homeless program, in fiscal year 2000.

Appropriate at least $40 million for the Projects for Assistance in Transition from Homelessness program in fiscal year 2000.

Appropriate at least $100 million for a targeted homeless addictive disorder treatment and recovery program in fiscal year 2000.

Appropriate at least $120 million for Runaway and Homeless Youth Act programs (Basic Center, Transitional Living, Street Outreach) in fiscal year 2000.

Appropriate at least $50 million for the Education for Homeless Children and Youth program in fiscal year 2000.

Appropriate at least $10 million for the Homeless Veterans Reintegration Program in fiscal year 2000.

INTRODUCTION

The need for health, social support, education, and employment opportunities for the nation's homeless children, youth, and adults far outpaces the availability of services to them. That homelessness is a life circumstance for an increasing number of Americans places even greater pressure on the range of homeless programs within the U.S. Department of Health and Human Services (HHS), U.S. Department of Education (ED), and U.S. Department of Labor (DOL). Those programs are: HHS's Health Care for the Homeless program, Projects for Assistance in Transition from Homelessness program, and the Basic Center, Transitional Living, and Street Outreach programs for runaway and homeless youth; ED's Education for Homeless Children and Youth program; and DOL's Homeless Veterans Reintegration Program.

While the activities funded by these programs alone will not end homelessness in this nation, they are nevertheless essential for assuring homeless persons' access to essential supports and for serving as gateways into to and extensions of mainstream systems. Accordingly, we urge Congress and the Administration to increase funding significantly for these homeless programs in fiscal year (FY) 2000. Appropriations increases for these programs and funding of a homeless addictive disorder treatment and recovery program would serve to redress the gap between supports available and increasing need for our nation's homeless population.

HEALTH CARE FOR THE HOMELESS

The Health Care for the Homeless (HCH) program (one of the programs within the consolidated health center cluster), within HHS's Health Resources and Services Administration, assures that homeless people have access to health care services through integrated systems of care. As well as providing primary care, diagnostic, preventive, emergency medical, pharmaceutical, and addictive and mental disorder services, HCH projects also conduct intensive outreach, case management, and housing, income, and transportation linkage activities. HCH projects are initiated and managed at the community level. HHS estimates that HCH projects serve only about one quarter of persons experiencing homelessness within a given year.

HCH projects and other health centers are overwhelmed by a burgeoning demand for services associated with increasing numbers of individuals without health insurance. This reality places an enormous burden on HCH projects and other community health providers, who are obligated to provide services regardless of the individual or family's ability to pay for them. Furthermore, an increase in the number of homeless people, brought on by recent changes to the Supplemental Security Income (SSI) program, which terminated income and health benefits for individuals with addictive disorders, and other socioeconomic factors, presents an expanded population of patients whom HCH projects and other community health providers are responsible to serve. The phase-out of Medicaid cost-based reimbursement to HCH projects and other health centers and the increased enrollment of Medicaid beneficiaries in managed care programs are reducing the amount of Medicaid funds available to HCH projects, thus presenting an additional major challenge to their ability to provide indigent care.

Increased federal funds will allow the HCH program to expand services to the three-fourths of the homeless population still without basic health care—both in the way of capacity increases of current projects and the establishment of new project sites—and enable HCH projects to remain financially viable in the increasingly market-oriented health service environment.

We urge Congress and the Administration to appropriate at least $1.025 billion for Consolidated Health Centers, including at least $88 million for HCH, in fiscal year 2000.

PROJECTS FOR ASSISTANCE IN TRANSITION FROM HOMELESSNESS

The Projects for Assistance in Transition from Homelessness (PATH) program, within HHS's Substance Abuse and Mental Health Services Administration (SAMHSA), makes funds available to states to assist them in providing outreach, screening and diagnosis, habilitation and rehabilitation, community mental health services, substance abuse treatment (for people with co-occurring addictive and mental disorders), case management, residential supervision, and limited housing services for homeless people with serious mental illness. PATH funds are allocated to all fifty states, the District of Columbia, and the U.S. territories, which then distribute the funds to a broad range of service providers—approximately 350 in number—who then deliver actual services.

While PATH has enabled many homeless people to return to secure and stable lives, limited funds preclude the program from reaching the universe of homeless people with serious mental illness. This group continues to grow as a result of a new wave of deinstitutionalization of patients from mental health facilities and the denial of services or premature and unplanned discharge brought about by managed care arrangements.

Additional federal funds are necessary for PATH to reach the substantial number of homeless mentally ill people still not receiving mental health services or losing mental health services.

We urge Congress and the Administration to appropriate at least $40 million for PATH in fiscal year 2000.

RUNAWAY AND HOMELESS YOUTH ACT PROGRAMS (BASIC CENTER, TRANSITIONAL LIVING, STREET OUTREACH)

Runaway and Homeless Youth Act (RHYA) programs, within HHS's Administration for Children and Families, support cost-effective, community-based services that protect youth from the harms of life on the streets and either reunify them safely with family or find alternative placements. The Basic Center Program provides grants to support temporary shelter for youth and counseling for youth and their families. The Transitional Living Program provides grants to support longer-term shelter as well as independent living services for youth. The Street Outreach Program provides grants to support street-based outreach and education to run-

away, homeless, and street youth who have been sexually abused or are at risk of sexual abuse.

RHYA programs provide crucial housing, education, life skills, and other opportunities and supports to vulnerable youth at a pivotal juncture in their lives—when they will be either plunged into homelessness and poverty or achieve stability and independence. Regrettably—for both the youth themselves and for the nation at large—the need for comprehensive services continues to outpace the ability of RHYA programs to provide them.

We note that the Administration's fiscal year 2000 budget proposes a $5 million increase in the Transitional Living Program as part of a broader initiative to assure the successful transition to adulthood for former foster youth and other youth in high-risk situations. Many TLP beneficiaries access these projects through Basic Center and Street Outreach projects, thus increases in all three RHYA programs are necessary.

We urge Congress and the Administration to appropriate at least $120 million for RHYA programs in fiscal year 2000.

HOMELESS ADDICTIVE DISORDER TREATMENT AND RECOVERY

HHS does not currently administer an addictive disorder treatment and recovery program targeted to the unique needs and life circumstances of homeless people, as it does for primary care and mental health. Instead, it is assumed that homeless youth and adults with addictive disorders will obtain treatment and recovery housing through the mainstream substance abuse treatment system.

But, the mainstream system does not adequately reach the homeless population. Homeless people, who are difficult to contact, are readily dropped from extensive waiting lists for mainstream treatment services. Further, community-based mainstream programs often refuse to accept homeless people. And community-based health care providers, such as HCH projects, lack the fiscal or programmatic capacity to provide addictive disorder treatment services to all in need.

For those homeless people who are lucky enough to enter the treatment system, lack of recovery housing frequently renders the treatment less effective. Successful addiction recovery requires the stability of continuous access to needed health care, enabling and supportive services, and a place to live. Homeless people, however, are lacking these necessities and are therefore likely to participate repeatedly in the same stage of the treatment cycle. They then are typically discharged back into the environments in which their addictive disorders took hold—streets or emergency shelters—where they are at far greater risk of relapse than if they had been discharged to a stable living situation. Thus, a "revolving door" emerges, resulting in a waste of precious human and financial capital.

Alternative models for delivering addictive disorder treatment and recovery services to homeless people that address these flaws in the mainstream system exist and have been proven effective in demonstration projects sponsored by HHS's National Institute on Alcohol Abuse and Alcoholism. Unfortunately, federal funding has not been made available to build on these findings in a concentrated way—a problem that a targeted homeless addictive disorder treatment and recovery program would address.

We urge Congress and the Administration to appropriate at least $100 million for an addictive disorder treatment and recovery program targeted to the unique needs and life circumstances of homeless people in fiscal year 2000.

EDUCATION FOR HOMELESS CHILDREN AND YOUTH

The Education for Homeless Children and Youth (EHCY) program, within ED's Office of Elementary and Secondary Education, assures that homeless children and youth have the opportunity to enroll, attend, and succeed in school. According to numerous studies, homeless children suffer disproportionately from health problems, nutritional deficiencies, and developmental delays. Schooling addresses these deficits by providing stable learning, continuous socialization, and food services during an otherwise chaotic and desperate time. Homeless children face significant barriers in gaining entry to public school and preschool programs due to the transience of their living situation. The EHCY program removes obstacles to enrollment and retention by establishing liaisons between schools and shelters and providing funding for transportation, tutoring, school supplies, and the coordination of statewide efforts to remove barriers. The EHCY program has made a difference for homeless children. The percentage of homeless school age children attending school regularly has increased from only 50 percent prior to establishment of the program to 86 percent in the 1990s.

Additional funding is necessary to enroll and retain in school the at least 14 percent of school-age homeless children and at least 70 percent or more of pre-school age homeless children still not enrolled. Further, school systems are being challenged to respond to the increases in family homelessness in their communities.

We urge Congress and the Administration to appropriate at least $50 million for EHCY in fiscal year 2000.

HOMELESS VETERANS REINTEGRATION PROGRAM

The Homeless Veterans Reintegration Program (HVRP), within DOL's Veterans Employment and Training Service, provides job training to homeless veterans. Although small, HVRP is the primary job training program accessible to homeless veterans. According to DOL, Job Training Partnership Act (JTPA) programs served only 2052 homeless veterans in the 1995 program year, compared to 7,432 homeless veterans served that same year through HVRP. While successful, HVRP has been able to serve only a small portion of the homeless veteran population due to insufficient funding.

We urge Congress and the Administration to appropriate at least $10 million for HVRP in fiscal year 2000.

SUMMARY

We urge Congress and the Administration to provide significant increases in fiscal year 2000 for the few programs targeted specifically for homeless children, youth, and adults. We look forward to working with Congress and the Administration to assure growth in the homeless programs of the U.S. Departments of Health and Human Services, Education, and Labor.

[In millions of dollars]

Program	Fiscal years—		Homeless orginal request
	1999 enacted	2000 President's request	
Consolidated Health Centers	925	945	1,025
(Health Care for the Homeless)	(79)	(81)	(88)
Projects for Assistance in Transition from Homelessness	26	31	40
Runaway and Homeless Youth Act programs (Basic Center, Transitional Living, Street Outreach)	74	79	120
Homeless Addictive Disorder Treatment and Recovery	.....	.....	100
Education for Homeless Children and Youth	28.8	31.7	50
Homeless Veterans Reintegration Program	3	5	10

LIST OF WITNESSES, COMMUNICATIONS, AND PREPARED STATEMENTS

SUBJECT INDEX

DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

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